



**Queen Margaret University**

**Edinburgh**

Doing Mad Studies: A Participatory Action  
Research Project to explore the experiences  
and impacts of being part of a Mad People's  
History and Identity course and the  
relationship between critical education,  
activism and emancipation

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## **Title of Study**

Doing Mad Studies: A Participatory Action Research Project to explore the experiences and impacts of being part of a Mad People's History and Identity course and to explore the relationship between critical education, activism and emancipation.

## **Abstract/Summary of research**

Mad People's History and Identity (MPHI) is a Mad Studies course delivered at Queen Margaret University (QMU). The course is a partnership including academics at QMU, Consultancy and Advocacy Promotion Service (CAPS), NHS Lothian and people with lived experience of mental health issues. LeFrançois (2016, p. v) provides a coherent definition of Mad Studies stating that "mad activist scholarship, a form of knowledge production or collective intellectual contribution that is embedded in Mad community interventions and actions."

MPHI is an exercise in critical pedagogy to facilitate "conscientisation" through the exploration of individual and collective experiences of madness, psychiatrisation and oppression. It aims to engage students in challenging dominant discourses, creating counter-knowledge and activist resistance to the Epistemic Injustice and oppression experienced by the mad community.

This PAR research proposed to explore the experiences and impacts of being part of the course. Its main focus was on the exploration of the relationship between participation on the course and activism. Congruent with the philosophy of the course, this research was committed to privileging the experiences, knowledge and histories of the user/survivor/mad MPHI students. A PAR group of four students, two partners from CAPS and the author co-produced this research. Data collection involved the peer interviews of nine MPHI students. The actions of the research were the generation of a Photovoice exhibition and the production of a film.

The research revealed that participation in the course had facilitated change in both mad and intersectional identities. It had given voice to experiences of distress, psychiatrisation and oppression. The collective experience had fostered support, solidarity and increased social capital. This included accessing new communities, occupations and engagement with social movements. The course had raised consciousness of personal and collective oppression resulting in agency and engagement with advocacy and activism.

Key words: Mad People's History, Mad Studies, Participatory Action Research, Activism.

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The most significant recognition goes to the PAR group who worked in partnership with me throughout this work. I would also like to thank all of the MPHl students who took part in the interviews, Photovoice exhibition and film that were the heart and soul of this research.

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Thank you to my partner Paul for his support and patience throughout the long journey to complete this Doctorate and my sister Molly for all her help and support.

## Glossary of Definitions and Abbreviations

Throughout this thesis, there will be a number of terms and abbreviations used. The author will normally use mad as are appropriated term to describe people with lived experience of mental health issues/ problems, mental illness and mental distress. The author will also privilege mental distress as it encapsulates a wider sociological understanding of this experience than other terms. “Mad Studies” and “Mad People’s History” will be in capitals throughout this work but other adoptions of mad will not be capitalised. The literature uses terms such as service-users, patients, consumers and psychiatric survivors. The author will privilege user/survivor/mad as a political position within this work. When quoting other scholars there is a diversity of terms used to describe the experiences, identities and labels used within and outwith the mad community. The author will respect this diversity of terminology within the literature and the research. This may cause confusion but is intended to challenge the homogenisation of the communities within the mad movement and respect self-determination of identity. The following table includes abbreviations that are frequently used throughout this thesis.

CAPS	Consultancy and Advocacy Promotion service
QMU	Queen Margaret University
MPH	Mad People’s History (Canadian course)
MPHI	Mad People’s History and Identity (Course at QMU)
OT	Occupational Therapy
PAR	Participatory Action Research
CPAR	Critical Participatory Action Research
DR	Dialogical Research
c/s/x	consumer, survivor, ex-patient
cis	cis gender

Table 1: Abbreviations

## **Declaration**

I declare that the work presented in this Doctorate Research Thesis for the Professional Doctorate in Health and Social Sciences is my own. All sources that have informed the content and contributed to the ideas presented have been acknowledged and referenced.



## 1. Chapter One: Introduction

### 1.1 Introduction and Context for the Research

Mad People's History and Identity (MPHI) is a critical education course delivered at Queen Margaret University (QMU). The course is a Mad Studies course designed to privilege the voices and histories of madness from the perspectives of those who have experienced it. The course was co-produced delivered and evaluated in a partnership with academics at QMU, CAPS and people with lived experience of mental health issues. This research project was inspired in part by the evaluation forms from the three MPHI courses and the student testimonies generated to support an application for a widening-participation educational award. The following testimony was submitted to the Glasgow Herald Education Awards (2016).

*.....Being on the Mad People's History course has been quite life changing for me. I was a student on the 2015 intake. Before being on this, I had a very small life having reduced it myself in order to feel safe. Many years of mental ill health had contributed to a destruction of my self-confidence. The course was a stepping-stone to me taking a fuller part in life again. Being on the course has had a huge impact on my confidence. Since completing it, I have expanded my life somewhat. I have attended a conference. I spoke at another conference, got involved with local advocacy, spoke about my experiences to drama and art therapy students and spoke on the introduction day to this year's intake of MPHI. All of this would have been impossible to me before the course (MPHI student).*

(Student testimony 2016)

It was one of many student evaluations that affirmed our decision to research the MPHI course. It was evident from student evaluations that participating in the course had resulted in important and diverse impacts. It motivated the author and partners of the course to explore in more depth the student experiences and the impacts of the course. There was also a collective desire to support the continuity of the course by producing evidence of impact.

The students and partners with lived experience are considered experts by experience on the MPHl course. The course has participation and inclusion of user/survivor/mad MPHl students and partners in every aspect of its design, data generation, analysis and dissemination. This led the group to decide on Participatory Action Research (PAR) as the natural methodology for this research project. The underpinning philosophy of PAR recognises the assets, experiences and knowledge of marginalised groups and their participation in leading the generation of knowledge within social research. This is supported by PAR advocate Fine who asserts:

.....Participatory action researchers ground our work in the recognition that expertise and knowledge are widely distributed. PAR further assumes that those who have been most systematically excluded, oppressed, or denied carry specifically revealing wisdom about the history, structure, consequences and the fracture points in unjust social arrangements. PAR embodies a democratic commitment to break the monopoly on who holds knowledge and for whom social research should be undertaken. (Fine 2008, p. 215)

MPHl students were invited to join a PAR group, to generate data about the experiences and impacts of the course. Four students and two partners from CAPS collaboratively designed and co-produced the research and its actions. The MPHl course leader was a member of the PAR group and is the author of this thesis. It is unusual in traditional research for a partnership project to be truly collaborative in designing the research, and it is more common for users/survivors to be invited to become involved in projects that are already established (Faulkner 2016). Involvement in research, unlike co-production does not imply equal partnership (Faulkner 2016). Co-production is defined by Needham (2009) as requiring users and partners to be involved in collaborative relationships in which partners can share power and be open to user expertise. Co-production is also dependent on the attitudes of professionals to users/survivors and their capabilities as experts by experience. This is illustrated by Palmer who states that “co-production therefore is based on the principles that public services should approach service users as assets who have skills that are vital” (2011, p. 2).

PAR as a methodology has a diversity of philosophical underpinnings that include various ontological and epistemological positions. The emphasis on the user/survivor students creating the research, the approaches used, the emancipatory goals of the knowledge produced and actions generated, led us to a critical research philosophy. This is defined by Henn et al who state that “Those researchers who identify with a critical approach reject both the positive and interpretivist approaches to social research, arguing that the aim of social research should be to change the world for the better” (2009, p. 27).

Critical Research has an epistemology of critical theory drawing its inspiration from critical theorists such as the Frankfurt Institute of Social Research (Crotty 1998). It has its origins in the work of social movement critical scholars predominantly Freire (1970, 1972), Fals-Borda and Rahman (1991) and Fals-Borda (1996). This critical epistemology aligns with the critical pedagogy of the MPHl course and in defining this research as Critical Participatory Action Research (CPAR). This CPAR has at its core the experiences and knowledges of user/survivor/mad MPHl students. Sweeney (2009) asserts that service user researchers are challenging their exclusion in knowledge production and the dismissal of their views and experiences.

Faulkner (2004) asserts that there are many different forms of what may be called survivor research which include: user-led, user-controlled research, and user involvement in research. This CPAR is collaborative, has user/survivor participation at its core and has been user-led in parts but not user-controlled. The areas in which there was collaboration include: deciding on the research questions, designing the research, generating data, analysing data and deciding on and implementing actions. There have been clear user-led activities of peer interviewing and the dissemination of the user/survivor PAR experience (Phillips et al. 2018).

The research philosophy and methodology of this research will be critiqued in more detail within Chapter Three which outlines the research strategy and design.

## 1.2 Main Research Aims and Questions

The PAR group collectively generated the research aims and questions of this project. The main aim of the research was to explore the experiences and impacts of being part of a MPHI course and to explore the relationship between critical education, activism and emancipation. Activism is defined by Love (2017, p. 409) as: “action as individuals are empowered to challenge marginalizing social contexts, ideologies, organisations, experiences, politics and discourses.” The PAR group discussions led us to the wider questions. What had motivated people to attend the course? What narratives had they constructed about their own experiences and history of madness? What were the experiences and the impacts of the course? Had the course led to activism? This research is complex as it aims to explore the experiences and impacts of the course and the relationship to activism. The PAR group were also very committed to the research promoting the mad experiences and histories of the students and their wider issues. The aims and questions encapsulate that duality of purpose.

The specific aims were as follows:

- To explore the motivations, experiences and impact of being involved in a Mad Peoples History course on mad-identified students.
- To develop a deeper understanding of Mad Studies as a critical pedagogy and its contribution to the generation of mad knowledge and the facilitation of activism from Mad People’s History student perspectives.
- To ascertain the contribution of Participatory Action Research to understanding the relationship between engaging in Mad People’s History, activism and emancipation.

The aims would be addressed by investigating the following research questions:

- What motivated the students to be part of a Mad People's History course?
- What narratives do the students construct around their own Mad History and mad identities?
- What are the experiences and impacts on the students of being part of a Mad People's History course?
- What can Participatory Action Research contribute to understanding the relationship between the engagement in a Mad Studies project, activism and emancipation?
- How can Participatory Action Research contribute to the advancement of Mad People's knowledge and the promotion of mad activism and Mad Studies?

### **1.3 Background to the MPHI Course**

The MPHI course was inspired by a project that emerged from the Mental Health Service User movement in Lothian, "Oor Mad History" (CAPS 2010). This was a community history project based at CAPS. The project was set up to record and promote the history of collective advocacy and activism by people with mental health issues involved in the service user movement in Lothian (Ballantyne et al. 2019). "Oor Mad History" and MPHI were influenced by collaborations with Mad Studies Canadian Scholars: Kathryn Church, Geoffrey Reaume and David Reville. Reaume created and delivered the first 'Mad Peoples History' (MPH) course in Canada. Church (2015, pp. 264-265) states that "this course works against the dominant psychiatric paradigm by placing the perspective of the 'mad, 'insane, or mentally ill at the centre of knowledge formation."

The partnership of MPHI was formed in 2013 involving QMU, CAPS and users/survivors/activists who had been involved with CAPS. NHS Lothian's Mental Health and Well-being Programme funded the course. To date the

partnership has delivered three courses in 2014, 2015 and 2016. The course awards 20 credits at Scottish Credit and Qualifications Framework (SCQF) Level 7.

CAPS and the user/survivor movement had a long history of MPH projects, before engaging with the University. This history, experience and knowledge were the think tank and heart of the MPHI course and this research project. Aligned to the organisational philosophy of CAPS, the researchers endeavoured to locate survivor/ user/mad experiences and knowledge at the core of this research. Through PAR this research has an underpinning philosophy of participation, inclusion, partnership, and dialogue.

MPHI is a higher education widening-participation project where lived experience of mental health issues is the only entry requirement. The module descriptor gives more details of the learning aims and objectives of the course (Appendix One). It addresses the exclusion of people with mental health issues from University. Students articulated this experience through the course evaluations. Student voices will be presented in italics throughout the thesis to differentiate them from quotes by scholars:

*.....The course had a really positive impact on my life that I can study. Having mental health issues doesn't mean that I don't have the right to go to University. (MPHI student)*

An additional issue identified by the students was that mental distress had interrupted their plans to go to University:

*.....What jumped out at me was the fact that it was at a University because I had been all settled as a teenager ready to go to University with provisional places at Cambridge University, then life happened and mental health happened, and I couldn't pursue what I wanted to pursue. I always felt that I had missed out by not being able to do that. Then I was unwell for such a long time - nearly thirty years - and the mere thought of going back into any sort of education just became more unrealistic over time. (MPHI student)*

MPHI has also attracted activists that are already involved with the mad movement. MPHI promotes the knowledge, history, experiences, narratives and activism of user/survivor/mad/activists that have been historically

excluded. A Photovoice assignment using photographs and narratives generates an ongoing history of the experiences of this user/survivor/mad/activist community. The flyer below gives details on the course aims and content.

MAD PEOPLE'S

HISTORY & IDENTITY



A FREE course by, about and for  
people who have lived experience of  
mental health issues.

For more information please contact

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E Mail: [EBallantyne@qmu.ac.uk](mailto:EBallantyne@qmu.ac.uk)

6 April - 11 May 2016





# What is 'Mad People's History and Identity'?

Mad People's History & Identity is an exciting new 5 week course starting soon at Queen Margaret University and open to anyone who has lived experience of mental health issues.

## **We'll cover topics including:**

What Is Mad People's History?  
A History of Confinement and Treatments  
What is Madness?  
Madness, Gender and Sexuality  
Activism



## **This course will give you the chance to:**

- Learn more about mad people's history and identity in a relaxed and supportive setting
- See yourself and others as "experts by experience"
- Connect with advocacy and activist organisations, locally, nationally and internationally
- Develop confidence and skills to prepare you for further or higher education
- Complete an optional piece of writing to achieve 20 nationally recognised university credits (20 credits at SCQF level 7)
- Discuss entry into college and university

**WHERE?** Queen Margaret University

**WHEN?** Wednesdays from 10.15am to 3.15pm, 6 April – 11 May 2016 .

**HOW MUCH?** FREE

**HOW DO I FIND OUT MORE AND APPLY?** Contact module coordinator Elaine Ballantyne:

**EBallantyne@qmu.ac.uk**  
**0131 474 0000 (ask for Elaine Ballantyne when prompted)**

This project is a partnership between Queen Margaret University, CAPS Independent Advocacy and NHS Lothian Mental Health and Wellbeing Programme.

Figure 1: Flyer MPHI

MPHI is a Mad Studies project and is the focus of this research. LeFrançois et al. provide a comprehensive definition of Mad Studies:

.....Mad Studies: An umbrella term that is used to embrace the body of knowledge that has emerged from psychiatric survivors, Mad-identified people, antipsychiatry academics and activists, critical psychiatrists and radical therapists. This body of knowledge is wide-ranging and includes scholarship that is critical of the mental health system as well as radical and Mad activist scholarship. This field of study is informed by, and generated by the perspectives of psychiatric survivors and Mad-identified researchers and academics. (LeFrançois et al. 2013, p. 337)

Mad Studies as a discipline emerged from Canada with Ingram (2016) being identified as coining the term. It is an emerging area of scholarship within the UK and has had a diversity of definitions. Costa (2014) emphasises the importance of the diversity of labels that identify this community and the importance of Mad Studies being firmly located within the voices of the mad community.

This Mad Studies research was co-produced by user/survivor/mad MPHI students, CAPS partners and the author of this thesis. There is a QMU vision that supports the MPHI course and this research. QMU (2016) outlines the vision, mission and values that align with both the MPHI course and this CPAR project. They include amongst others to be a University of ideas without borders that is committed to social justice. The MPHI course has a dual aim. Firstly, it aims to widen participation to the University. Secondly, it aims to create a critical pedagogical space that facilitates conscientisation, counter-knowledge, activism and emancipation for user/survivor/mad students. This CPAR project collaborated with students and partners to generate knowledge about the relationship between participating on the course, activism and emancipation. Emancipation is an envisaged outcome of activism. The oppression experienced by the mad community is an intersectional picture that is explored within the literature.

## 1.4 Madness and Oppression

There is evidence to suggest that psychological distress has an impact on the social mobility of young people. In their West of Scotland survey, Sweeting et al (2016) investigated the evidence of health inequalities in adolescence according to Socio-Economic Position (SEP) and whether or when they emerge in early adulthood. They report a correlation between poor mental health at the age of eighteen and associated disadvantaged SEP at the age of twenty-four. This suggests that poor mental health in early adulthood may have an impact on future life chances including participating in education.

However, the Scottish Government review on the life opportunities of young disabled people in Scotland asserts that there is a gap in this evidence on socio-economic disadvantage and mental health in young adults. In relation to accessing University, the age of the onset of mental health issues is important. The paper highlights issues for disabled young people and includes young people with mental health issues within this grouping. It reveals the participation issue of young disabled people by asserting that they have a lower rate of participation in Higher Education (The Scottish Government 2017a).

There is clear evidence in the literature about the importance of adolescence in relation to poor mental health and future SEP, health and life opportunities. There is also evidence of issues concerning participation in Further and Higher education for young people with mental health issues. The students on the MPHl course were diverse but many had not been able to go to University or finish University because of mental health issues. One of the students described this experience:

*.....I felt locked outside of education all my life because of poverty, parental control or other circumstances. It has been very rewarding to be included finally in my fifties (MPHl student)*

The literature suggests that discrimination resulting in unequal access to education is an ongoing issue for young people with mental health issues.

The mad community, however, is not a homogenised group and the literature has evidenced an intersectional picture of madness and oppression. Black, feminist, legal scholar Kimberlé Crenshaw (1989) originally developed the concept of intersectionality in her critique of the need to demarginalize the intersection of race and sex. This was in relation to anti-discrimination doctrine, feminist theory and anti-racist politics. She asserts that a single axis framework cannot accurately address the complexities of how black women are oppressed by sexism and racism.

The latest UK based Mental Health Foundation (MHF) report asserts that mental health problems are higher depending on who you are in the world. There are higher risks for people in poverty, children and young people, women, disabled people and people from Black, Asian and Minority Ethnic (BAME) communities. The intersectionality between identities and social circumstance increases your risks of developing mental health problems and subsequently experiencing oppression. Factors such as material, social and health inequalities are highlighted as leading to mental health inequalities and subsequent impacts. The report states:

.....Certain population subgroups are at higher risk of mental health problems because of greater exposure and vulnerability to unfavourable social, economic, and environmental circumstances. These intersect with factors such as gender, ethnicity and disability, in many cases with devastating consequences for individuals and their families (MHF 2018, p.3)

The MPH1 course and this PAR occur within a Scottish context. Mental health issues in Scotland are reported by the MHF who state that “between 2012 and 2015, one in six, (15%) of adults in Scotland report symptoms of a mental health condition” (2016a, p. 5). There is a larger intersectional picture behind this statistic reported by Gordon et al who assert:

.....Health problems are immensely varied and almost impossible to summarise. The very clear exception is mental health. Across most population groups, there is a repeated finding of diminished mental health because of the pervasive and insidious effects upon wellbeing of experiencing personal prejudice, collective discrimination and structural exclusion from full and fair participation in Scotland’s material

prosperity, social life and power structures. These effects may also contribute to poorer health-related behaviours. (Gordon et al 2010, p.1)

The Scottish Government review on the life opportunities and young people in Scotland reveals that this is a growing area of concern for young women and asserts:

.....The evidence suggests that this higher level of mental health issues among young women manifests earlier in adolescence. NHS Health Scotland found that girls reported slightly lower life satisfaction and mental wellbeing, and were more likely to have common mental health problems and emotional symptoms. (Scottish Government 2017a), p.44)

Millard and McCartney assert that there are inequalities in mental health outcomes by age, sex and deprivation and highlight the issues for men within Scotland.

.....Young adults and those living in the most deprived communities are at greatest risk of worse mental health. Women report worse mental health and lower wellbeing than men on survey measures, but men are more likely to be alcohol dependent, misuse drugs and die from alcohol- and drug-related conditions, and from suicide. (Millard and McCartney 2015, p.1)

The report also highlights the intersectionality with transgender and sexual orientation with higher levels of poor mental health reported by transgender individuals (66.7%) and bisexual women (63%). In addition, in a LGBT survey in Scotland (2013) 40% of LGBT youth aged between 13-25 consider themselves to have a mental health condition compared to 25% of the population overall (MHF 2016a). There are issues within Scotland regarding data on the BAME community. Millard and McCartney conclude that:

.....Data were available for only a limited range of measures of health and wellbeing and for a limited range of equality groups. For example, we would have liked to have examined outcomes by ethnicity, religion and for specific groups such as veterans, but there were insufficient data to do so (Millard and McCartney (2015, p. 23)

There is a lack of data about the BAME communities in Scotland. This lack of adequate and sufficient data contributes to the problems of misdiagnoses, under-diagnoses and fewer treatments accessed (MHF 2016b). The MHF

states that in general, there is a UK picture that the BAME communities are more likely to be diagnosed with mental health problems, admitted to hospital, experience poorer outcomes and more likely to disengage from mainstream services (MHF 2016b).

There were intersectional issues within the MPHl course and this research. The three cohorts of MPHl students and the students involved in this research were predominantly women. There were in total 48 students who completed the course between 2013 and 2016 including eleven men and thirty-seven women. Students volunteered to be part of the research. The PAR group consisted of seven women. There were eight female students interviewed and one male student.

We do not have definitive numbers in relation to class, sexual orientation and disability. What is significant is the race and ethnicity of the participants on the course and the research. Over the three years there were only two students from the BAME community and only one of them was involved in the research. The gendered and ethnocentric dimensions of the course and the research have to be acknowledged. The literature suggests that there are more women with mental health issues in Scotland and that men are less likely to seek support from services for mental health than women. The BAME community constitutes 4% of the population in Scotland (National Records of Scotland 2011). Black men within the UK report that the racial stereotyping and cultural insensitivity they experience in services, impacts on engagement. The cohort PAR participants may represent an ethnocentric Scotland or a lack of inclusion of the BAME community or both.

There is also a debate within the Mad Studies literature on the importance of intersectionality and the imperative of this emerging discipline's inclusion of an intersectional analysis of madness (Poole and Ward 2013 ; Diamond 2013; Gorman 2013; LeFrançois 2013; and Gorman and LeFrançois 2018). The debates within the Mad Studies literature on intersectionality will be more expansively explored and critiqued within the literature review in Chapter

Two. It is clear that there is an intersectional picture and there is a legislative and policy response.

### **1.5 Policy Background**

The Equalities Act (2010) offers a legislative response to the discrimination and exclusion experienced by marginalised populations within society. It introduced nine protected characteristics, embedded within this legislation. It is against the law to discriminate against someone because of a protected characteristic of: age, disability (this includes mental impairment), gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief (includes non-belief, sex and sexual orientation). Service user guidance within the Legislation states: “Understand your rights to be treated equally and free from discrimination when buying goods or accessing services, including protection against harassment and rights to accessibility (Equality and Human Rights Commission (2019). Most mental health policy documents in line with the Equalities Act (2010) approach the inequalities faced by marginalised people in a group-by-group approach. Gordon et al. problematises this approach:

.....Taking a group-by-group approach appears to deny the intersections between groups that often define disadvantage much more sharply than a single dimension. People are not one-dimensional, defined by a single characteristic. (Though, in some cases, discrimination based on one characteristic can be a dominant factor in shaping an individual's or group's whole experience of life). People are complicated. The ways in which we define ourselves are complex. Our physical characteristics, histories, influences, behaviours, cultures and subcultures are all exceptionally intricate narratives that we use to identify ourselves. We are all constantly defining and redefining different aspects of ourselves. (Gordon et al. 2010, p.1)

There are government responses to the mental health situation in Scotland through a new Mental Health Strategy (2017-2027). The new Mental Health Strategy for Scotland (Scottish Government 2017b) offers a framework to respond to the needs of people in Scotland who experience mental health issues. Underpinned by the consultation with the Scottish Human Rights

Commission service user involvement and rights are clearly stressed as a priority:

.....Participation and human rights are core parts of the framework's priorities and the strategy asserts that to realise the human rights of people with mental health problems what is required is to embed a human-rights based approach across all its activities using the PANEL approach of: "Participation, Accountability, Non-discrimination and equality, Empowerment, and Legislation (Scottish Government 2016b, p.33).

Aligned with Mad Studies is an emerging challenge within policy to challenge the dominance of the biomedical approach and the promotion of meaningful user involvement in participatory mental health service and policy projects. The United Nations Mental Health Report (UNHRC 2017), makes recommendations regarding addressing the dominance of the biomedical model approach in mental health. This includes the establishment of meaningful and participatory frameworks informing public policy. It stresses that service users are involved in the design, implementation, delivery and evaluation of mental health services, systems and policies.

This CPAR aligns with the vision of the University and the rhetoric of mental health policy on rights and participation. MPHl aims to foster social mobility and inclusion for a group of people whose access to Higher Education has frequently been impeded and disrupted by mental health issues. This CPAR aims to explore the experiences and impacts of participation in the MPHl course located within Higher Education.

The context of the MPHl course within a University is relevant as there are debates within Mad Studies focussing on partnership projects within academia. This relationship has been critiqued within the literature as posing both opportunities and challenges to oppression. There are differences in culture and processes between a University and user/survivor organisations. The complexities of mad scholarship within a neoliberal University creates numerous challenges for both mad-identified scholars and mad-positive academics. These include: institutionalised sanism (Landry and Church 2016), evidence-based teaching, managerialism and the organisational



separation of instructors and subjects that impede alliances with other social movement scholarship (Church 2015). QMU has embraced this work and it has support from academics in both Health Sciences and Public Sociology. Having a diverse partnership enriches the project, supports sustainability and protects against co-option.

Within the University an opportunity and challenge has been promoting the impacts of the course, celebrating its successes and maintaining a high visibility. The course was shortlisted for a Glasgow Herald Education Award for widening-participation in 2016. An opportunity has also been the passion of the CAPS partners and the MPHI students for the participation in embedding meaningful user/survivor/mad/activist input to numerous courses within the University. The students and team have presented at Mad Studies, Disability Studies, Critical Perspectives and Health Professional conferences throughout the UK and internationally. Students have published articles about the MPHI course (Mehdi 2013) and the CPAR (Phillips et al. 2018) in Asylum magazine.

The opportunities locating MPH projects within QMU has generated assets that have outweighed the challenges however this neoliberal context is not without risks as asserted by Scandrett and Ballantyne:

.....In its small way Mad People's History and Identity provides seeds of what might undermine the neoliberal University, especially through the public health recognition in the receipt of NHS funding. As such, however, it is also vulnerable to the progressive attack of neoliberalism in both universities and the health service, subject to severe austerity cuts and increasing marketisation. (Scandrett and Ballantyne, 2019, p.11)

## 1.6 Professional Relevance

Within the University, my roles as an Occupational Therapist, lecturer and researcher overlap. Within my role as a lecturer I teach Occupational Therapy students and other student groups. I am involved with the MPHI Critical Education Course with user/survivor/activist/mad students. In this

context the professional relevance of this CPAR work spans all my roles. It is most aligned to my role as teacher on the MPHl course. My roles are underpinned by drivers for a critical approach within Occupational Therapy and education. I also embed Mad Studies and critical perspectives in my teaching to all student groups. There is a current driver within the Occupational Therapy profession to move from working with individuals to communities. It advocates using occupations to improve the health and social inclusion of communities experiencing oppression (Whalley Hammel 2016). There is also a growing body of Occupational Therapy literature advocating for a critical discourse that is political and structural in its critique. However, Whalley Hammel and Iwama promote a critical practice of Occupational Therapy to promote human well-being:

.....A philosophical commitment to human wellbeing requires a critical practice of occupational therapy: innovative practice that acts on the knowledge that human well-being cannot be achieved solely by enhancing individuals' abilities, and that consequently endeavours to address the inequitable conditions of people's lives. (Whalley Hammel and Iwama, 2012, p.392)

The task of critical pedagogy is to bring members of an oppressed group together to develop a deep awareness of the social structures that oppress them individually and collectively which results in resistance and counter-hegemony and emancipation (Giroux 1983, p.111). Hocking (2009) cautions against Occupational Therapy adopting a normative stance shaped by cultural assumptions. She asserts this may result in reinforcing hegemonic values and dominant frameworks within occupational theories, and by extension, their transmission into education. Ragumondo's (2011) concept of "occupational consciousness" strengthens embedding critical pedagogy in Occupational Therapy education. "Occupational consciousness" promotes an awareness of the dynamics of hegemony by challenging exclusionary social practices which are taken for granted. This establishes an appreciation of the role of the personal and collective occupations of daily life in perpetuating hegemonic practices with resultant consequences for individual and collective well-being (Ragumondo, 2011).

There is limited Occupational Therapy literature on Mad Studies. The only article is from Le Blanc and Kinsella (2016) who have added to this literature, from a Canadian perspective, with a critique of sanism, Epistemic Injustice and the implications for knowledge generation. LeBlanc and Kinsella (2016) assert that sanism marginalises the knowledges of mad people. They advocate that mad counter-knowledge is required as an action of epistemic resistance by the mad community.

Within an academic context, which is educating the next generation of Occupational Therapists, there is a need to embed not only meaningful survivor knowledge and narratives within the curriculum but also to promote critical pedagogy and survivor research within the University. As an Occupational Therapy academic, there have been opportunities and challenges within a neoliberal University context to promote MPH through critical pedagogy and CPAR. It is, however, outwith the remit of this thesis to expansively critique the contribution of Occupational Therapy literature to critical pedagogy or CPAR.

There is a dearth of literature on the experiences and impacts of being a student of a MPH course within the UK. Critical education claims to promote activism and emancipation through challenging the dominant discourses and facilitate “critical consciousness”. This Mad Studies research aims to explore whether activism and emancipation have been outcomes. There is also no Occupational Therapy literature or research on MPH and only one article on Mad Studies. There are clearly gaps in the literature of an emerging area of scholarship. As part of the “psy complex”, Occupational Therapy has a choice to make on where it is positioned in relation to the mad movement. Occupational Therapy education has choices: to produce uncritical partners of the “psy complex” or to become an ally to the mad movement. It has the potential to support mad-identified students and foster mad-positive students committed to praxis and activism. Critical pedagogy and CPAR offer opportunities to fulfil the latter.

At its core, Mad Studies literature suggests that there is a need for knowledge production about madness from those who have experienced it. By including mad-identified people in knowledge production, academics can ensure meaningful participation and prevent colonisation and marginalisation. This Mad Studies research aims to generate new knowledge on the experiences and impacts of being involved in this MPHl project. Our motivations are captured by Campbell and Oliver (1996): “We approach the research task as activists trying to make sense of our actions, not as researchers trying to be where the action is” (p.24).

### **1.7 Thesis Structure**

Following this introduction, Chapter Two is a literature review on Mad Studies. The literature is limited within this emerging discipline. This chapter will explore and critique the following themes emerging from the literature: the philosophy and aims of Mad Studies, MPH and MPHl and the relationship between Mad Studies and the academy.

In Chapter Three, the research strategy and design are presented. The critical philosophy, critical epistemology and CPAR as a methodology using a dialogical approach will be discussed. The method of using peer interviews to generate the data involving photo elicitation as a technique is justified. The dialogical and participatory approaches to generative thematic analysis are critiqued. The ethical considerations, values, trustworthiness and limitations of the research are interrogated. The choice of creating a film and a Photovoice exhibition as the actions of the CPAR are discussed.

Chapter Four sets the scene for the findings of the research. Chapters Five, Six, Seven and Eight present the four overarching themes, themes and subthemes that were generated by the thematic analysis of the data. Each chapter explores the user/survivor/mad perspectives of the participants. Photovoice images created on the course and discussed in the interviews will be woven throughout the results. This will illustrate the student interpretation of the images to elicit data on their mad identities and histories. The

discussion of the key findings will be presented in a summary. There will be discussion after each chapter critiquing the findings in relation to the Mad Studies literature and relevant intersectional social movement literature and underpinning sociological theories.

In Chapter Nine, this work is concluded by reflecting on the research experiences and findings. There is an exploration of the knowledge generated in relation to the research aims and questions.

In Chapter Ten, there is a reflexive exploration of the CPAR methodology which provides a critical reflexive account of the challenges, opportunities and experiences of this CPAR project. This includes the reflections of the user/survivor/mad/activist students who were part of the PAR group. The realisation of the aims and the rigour of the research will be critiqued. Finally, there is a critique of the knowledge generated by the research and an exploration of its potential importance in relation to the Mad Studies literature, research, practice and the MPHl course. The next chapter will review and critique the literature pertaining to the philosophy and aims of Mad Studies, Mad Studies relationship to academia and the MPHl project at the centre of this CPAR.

## **2. Chapter Two: Literature Review**

### **2.1 Introduction**

Mad Studies is described as an emerging discipline within the UK (Beresford 2014). With its origins in Canada, it has been discussed and promoted by Mad Scholars and activists internationally. Ingram a Canadian scholar was credited with creating the term “Mad Studies” (Ingram 2016). He suggests that this is not an emerging discourse and that the ideas of the mad movement have been in circulation for over twenty years in Canada and the rest of the world. An important development however has been the first two named Mad Studies texts: *Mad Matters* (LeFrançois et al. 2013) and *Searching for a Rose Garden* (Russo and Sweeney 2016). Menzies et al outline the purpose of the first Mad Studies critical reader from Canada they assert:

.....The matter of Mad Studies-and that Mad does matter- is the express purpose of this reader; we explore here the various ways to take up the matters of “psychiatrization”, “madness”, the oppression and agency of Mad subjects, and the battle against psychiatry and psychiatric discourse. (Menzies et al 2013, p.1)

Menzies et al (2013) encapsulate the focus of Mad Studies as offering the opportunity to explore the experiences of madness, psychiatrisation and the oppression and agency of the mad community. It also asserts that Mad Studies has an ultimate aim to challenge the dominant discipline of psychiatry and its powerful discourse. It promotes the importance of agency within the mad community in order to provide alternative discourses and responses to madness. Russo and Sweeney (2016) present an international textbook and LeFrançois suggests its strengths lie in its focus on psychiatric survivor knowledge and mad activist arguments. She asserts:

.....this volume represents a crucial and unprecedented account of what Mad Studies is all about. Notably, it is almost wholly written by psychiatric survivors.....As such this volume contains so many of the important arguments-mad activist arguments-that link together the diverse issues subsumed within the umbrella of Mad Studies. (LeFrançois 2016, p. vii)

The mad movement is a diverse community of: anti-psychiatry, critical psychiatry, Mad Studies scholars and user/survivor/mad perspectives. This diversity has been conceptualized as “constituencies” by Diamond (2013, p.65). This review will explore the perspectives and analysis of all the constituencies of the movement as they relate to this research. The critical discourses of allied social movement scholars and activists have informed the development of Mad Studies. They share the intersectional experiences of oppression and the subsequent development of critical pedagogies and theories to challenge the dominant discourses and structures that create and maintain oppression. This review will incorporate theoretical literature from Mad Studies scholars, user/survivor/mad/activists debating the intersectional experiences of madness. It will explore the relationship of Mad Studies with allied social movements scholars, critical pedagogies and theories from Disability Studies, Queer Studies, Feminist Studies and Race Studies. Due to limited wordage, this will focus on how they intersect with Mad Studies and will not be a critique of the diverse literature from all these pedagogies. The first section will focus on “What is Mad Studies?” As an emerging discipline, the literature is predominantly focused on the philosophy aims and actions of this new field of study.

The literature includes debates about the contribution of allies as partners within Mad Studies. The second part of the review will explore the debates regarding the contribution of mad-positive allies and partnership working within academia. The MPHI course and this CPAR project are located within academia. There is a small body of work that critiques the opportunities and challenges of this context and partnership with academics. There will also be a focus on the challenges and concerns around the relationship with academics within the neoliberal University. The debates around co-option and colonization of survivor knowledge will be explored and the contribution of academia to the mad movement critiqued.

Literature, specifically on Mad People’s History (MPH), is Canadian in origin with a growing body of work being produced by Mad Studies scholars

(Reaume, Reville, Landry and Church). There is limited literature on the Mad People's History and Identity course (MPHI) which is the subject of this research. There are two Asylum magazine articles. One is from a survivor participant involved in planning the course (Mehdi 2012) who discusses the origins of the course and the experience of presenting at a conference in Finland. The second article is from a participant in the research and the survivor researchers who co-created the research. (Phillips et al, 2018) discuss the aims of the research and their experiences of Photovoice. There is however MPH literature in press: Scandrett and Ballantyne (2019), Ballantyne et al. (2019) and Gorman and Ballantyne (2019). The last part of the review will explore and critique the MPH literature and its relationship to the MPH literature.

Ingram's (2016) assertion that the ideas of the mad movement have been in circulation in Canada and the rest of the world for over twenty years, emphasises the centrality of survivor histories, voices and resistances in the development of Mad Studies. However, the historical literature cannot be retrospectively included under the discipline of Mad Studies, therefore this review will focus on the literature that is clearly identified as Mad Studies. It could be argued that an inclusive and expansive literature review of Mad Studies should include: all the writings, art, actions and theoretical perspectives of all constituencies of the mad movement, reflecting that they are historically and theoretically interwoven. This review is designed to explore, synthesise and critique the literature about the knowledge, theories, practices and resistances that have emerged under the discipline of Mad Studies over the last decade. There is, however, a dearth of empirical research on this emerging discipline that presented challenges for this review. Mad Studies also includes underpinning philosophical and sociological theories that will be explored in relation to its aims. The literature review will identify relevant gaps in the literature that have provided the justification for this research project.



In order to develop this research, an exploration of the wider literature is required. This guides, critiques and explores the debates around Mad Studies, MPH and MPHI. There is a growing body of literature around Mad Studies as an emerging discipline. The literature relevant to this research is clustered around three themes: What is Mad Studies? Mad Studies and Academia and Mad People's History.

What is Mad Studies? This is the first theme that is evident in the literature. In order to understand the emergence and development of projects, such as MPH and MPHI that are clearly identified as Mad Studies projects, the history, underpinning philosophy and aims require exploration and critique.

## **2.2. What is Mad Studies?**

The definition of Mad Studies is debated within the literature. Beresford and Russo (2016) assert that there is debate around what constitutes this emerging discourse: "There is no precise or agreed definition of Mad Studies, which is perhaps not surprising since it is still at a relatively early stage of development" (p.271). Ingram (2016) describes Mad Studies as an 'in/discipline' and a multi vocal praxis. It is not owned by anyone, it is evolving and no one defines its borders or has authority over the direction it may go in (Costa 2014, LeFrançois et al. 2016). Ingram expands and problematises this duality:

.....The way I described Mad Studies in the paper at Syracuse was as an in/discipline, by which I meant that it was both a discipline and an indiscipline. We are always caught in these doubles, and there is no way around this. (Ingram 2016, p.13)

What is clear within the literature is the history of Mad Studies in relation to the psychiatric user/survivor movement. The history of Mad Studies and its relationship to the user/survivor movements is reinforced by Beresford and Russo (2016): "Mad Studies does not emerge in isolation. It has connections with other radical mental health and user/survivor-led initiatives, not least, the international "Mad Pride movement" (p.270). However LeFrançois et al. (2013) stress that it has not solely originated from the user/survivor

community and that it has had a wider influence stating that “we are not locating “Mad Studies” as originating solely within the community of people deemed Mad, but also as including allies, social critics, revolutionary theorists and radical professionals” (p.2). The literature suggests that it has emerged and been shaped by the wider mad movement and its critical allies. At its roots, Mad Studies has been informed by the user/survivor, critical psychiatry and anti-psychiatry movements.

It has also been an intersectional discipline that has been influenced and informed by the struggles and pedagogies of allied social movements. Mad Studies has benefitted from historical and ongoing alliances with other marginalised groups and benefitting from intersectional experiences. Costa (2014) asserts that Mad Studies has a long history with survivor movements and has been influenced by their approaches, methods and research. She highlights the influences from Women’s, Queer and Critical Race Studies.

Mad Studies has grown from within the mad movement and from allied social movements and their critical pedagogies. The ideas and resistances that have influenced the development of Mad Studies from the user/survivor movement and other critical allies have been around for several decades. Mad Studies has emerged from and is therefore inextricably interconnected with the mad movement. A movement, described by (Gorman and LeFrançois 2018), that celebrates mad experiences without pathologising, glamorising or effacing the experience of distress.

Within academic and activist contexts, mad has been reclaimed and Mad Studies is becoming a recognised discipline. There is no consensus on its use as a positive individual, collective or political term by people who have experienced mental health issues. Reville, a Canadian Mad Studies scholar, has created new terms for this emergent discourse they are: mad-identified: a person identifying themselves as mad, mad-positive: refers to a person who does not identify as mad but supports the goals of those who do (Reville 2013, p.170). In their research about a social model of distress, Beresford et al. (2010) encountered user/survivors who rejected mad as helpful due to it

being, negative, labelling and stigmatising. One participant asserting: “I stick to my guns and I don’t like the word madness. I think it ought to be done away with” (p.21). Activists and scholars also contest its use and reappropriation. Burstow (2013) asserts that there are positives in mad language as it “facilitates celebration and pride” (p.85) but she advocates the refusal of terms such as survivor, inmate and patient. She asserts the usefulness of mad language will depend on the analysis behind its use and the care with which it is used. Plumb (2015) questions how useful and acceptable mad is to the user/survivor movement. Russo (2016) asserts that the experiences of being labelled feared and othered are more connecting than madness and that madness cannot serve as a personal or collective identity. He emphasises: “the experience of madness is always a highly personal matter” (2016, p. 65).

Fabris (2016) asserts that “mad is an historical rather than a descriptive or essential category, proposed for political action and discussion” (p.139). There are debates within the literature about the use of the term mad. Some authors choose to capitalise “Mad” to differentiate it as critical and political (Fabris 2013). Mad is historically a term of abuse directed towards people who have experienced mental illness, mental health problems and mental distress. The literature suggests the reappropriation of the term mad is a conscious political action by activists and Scholars to reclaim a pejorative term and make it positive. Church, a Canadian Mad Studies scholar, relates this process to activism and self-identity:

.....In the context of a rich debate here, perhaps the most useful thing I can say is that the term “mad” is an activist interruption in the discourse of “mental illness.”It makes you stop and say “What?” and in that space of sudden confusion, there is a chance we could change the subject. So one thing the word does is create an opening into “something otherwise” as part of a long struggle to reclaim words and the right to self-identify. To claim “madness” is to invoke a strand of human history that pre-dates psychiatric dominance. (Church 2013a, p.1)

There are many overarching claims within the literature that define the aims and outcomes of Mad Studies. LeFrançois et al. (2016) assert that it is “a collective project that is developing primarily out of the politicized

discussions, theorizings, research, interventions, and social actions taking place within our mad communities” (p.1). Menzies et al (2013) assert that it is “a project of enquiry, knowledge production, and political action devoted to the critique of psy-centred ways of thinking, behaving, relating, and being” (p.13). The literature emphasises the importance of the centrality of mad communities in knowledge production and political action. LeFrançois (2016) asserts that Mad Studies should occur in many spaces within and outwith the academy but not without the mad community. Central to the philosophy of Mad Studies is that it should have the people who identify as mad at its analytic core. Costa provides an expansive definition of Mad Studies that puts people that identify as mad (and other identities) at the core of all of its purposes and actions:

.....Mad Studies is an area of education, scholarship, and analysis about the experiences, history, culture, political organising, narratives, writings and most importantly, of the PEOPLE who identify as: mad; psychiatric survivors; consumers; service users; mentally ill; patients, neuro-diverse; inmates; disabled. (Costa 2014, p.4)

Mad Studies scholars assert it should be firmly located within the historical and everyday experiences of madness distress, psychiatrisation, oppression and resistance. O’ Hagan (2016) asserts that mental distress must be viewed from the perspective of those who have experienced it and viewed as an experience that, whilst challenging, has value and meaning. The value and meaning of lived experience generates knowledge that is conceptualised as experiential knowledge. Beresford (2016) asserts that the experiential knowledge of madness has been historically marginalised and devalued by the idea of expert experience. The dominant positivist analysis reduces the credibility and legitimacy of survivor knowledge within research, policy, practice and learning. Russo and Beresford (2015) assert:

.....The omnipresent psychiatric narrative of mental illness has always had its counter narrative, the life stories of people labelled mad. The relationship between these two accounts has always been one of domination: mad voices have been and continue to be not heard, overwritten, silenced or even erased.” (p.153)

Crepaz-Keay and Kalathil (2013) assert that “Mad Studies will correct the balance of the overwhelming majority of material written about those who are labelled mad by those who do the labelling and those who study them” (p.5). Beresford (2016) asserts that the promotion of experiential knowledge offers hope to change individual and societal understandings of the difficulties facing marginalised groups. There has been an historical exclusion of the mad counter-narrative and meaningful survivor knowledges and experiences in practice, education and research. This has more recently included the sharing of personal stories of distress and madness, however, the promotion of the ‘personal story’ is not unproblematic.

Costa et al. (2012) critique the appropriation and over-reliance on the psychiatric patient’s ‘personal story’. They assert the sharing of lived experience stories have historically been used to campaign for change within and outwith the psychiatric system. This, however, has led to the system using such narratives for their own ends in practice, research and education. This has resulted in ‘lived experience’ narratives becoming ‘patient porn’ and ‘disability tourism’ as opposed to agents of change. They question the impact of personal stories and offer a clear warning to the mad community about the need to reclaim their stories, politicise them and view with suspicion those who want to capture and commodify for their own agendas. They advocate:

.....Those who reveal their stories to consider doing so in a way that is politically accountable and focused on social justice change. And through this small act of organizing resistance, we inform those that solicit stories that we are now asking, in whose interest? (Costa et al. (2012, p. 99)

Whilst narratives have become part of the mainstream (Russo and Beresford 2015) assert that this frequently amounts to tokenistic inclusion of survivor narratives. They are frequently co-opted, dominated and undermined and ultimately removed from the people who own them (Costa et al. 2014).

Penny and Prescott (2016) support this position and assert that co-optation of survivor knowledge by the dominant group may involve the appropriation of personal narratives. This ultimately results in a disempowering

interpretation that undermines the goals of marginalised groups. The concepts from Mills' theory of the sociological imagination may be helpful. The sociological imagination refers to the relationship between individual troubles and the large social forces that are the driving forces behind them. These are described as 'personal troubles' and 'public issues' (Mills 1959, p. 4).

The debate within Mad Studies is centred on the importance of sharing personal narratives versus the political purpose of mad narratives. The assertions are that collective counter-narratives, analysing 'public issues', provide an opportunity to produce knowledge that challenges the dominant discourses and the oppression of social institutions.

This debate has been evident in the critiques of the Women's Liberation Movement. Feminist scholar Hanisch is credited with the term "The Personal is Political". She defends the attack on the consciousness raising groups of the Women's Liberation movement as not being political: "women getting together in consciousness-raising groups to discuss their own oppression as "naval-gazing" and "personal therapy"—and certainly "not political." ... they belittled us no end for trying to bring our so-called "personal problems" into the public arena" (Hanisch 2006, p1).

Mad Studies offers a critical pedagogy to the mad movement that offers analysis of both the 'personal troubles' and 'public issues'. There is, however, a strong position for the need to bring the personal into the public with a political vision. This vision aims to facilitate counter-hegemony, collective resistance and the creation of positive alternatives. This CPAR has an aim to make public the MPHl students personal and collective experiences of the course. It also aims to explore the wider issues of their histories of madness. It also aims to promote their voices through a Photovoice exhibition and a film that is underpinned by a political aim to promote MPHl as a politicised space for activist scholarship.

Mad Studies is an exercise in critical pedagogy. "Mad Studies is an exercise in critical pedagogy-in the radical co-production, circulation, and consumption of knowledge" (Menzies et al. 2013, p.14). Critical pedagogy as a term is attributed to Giroux in (1983) who asserts that critical pedagogy requires a vision of what could be possible and that links struggle to new human possibilities. The theoretical concepts most aligned to Mad Studies include the theories of Gramsci, Giroux, Foucault and Freire. Gramsci's theory of hegemony is particularly relevant to Mad Studies as it refers to the social control of subordinate groups by a dominant group through intellectual and moral control (Gramsci 1971). He argued that leaders reinforced useful assumptions of truth (Darder et al 2016). Foucault added to this discourse by questioning these "regimes of truth" as legitimised by the power relations within society (Darder et al. 2016). Foucault problematises the legitimacy of truth, knowledge and power stating:

.....The problem is not changing people's consciousness' or what's in their heads-but the political, economic, institutional regime of the production of truth. It's not a matter of emancipating truth from every system of power (which would be a chimera, for truth is already power) but of detaching the power of truth from the forms of hegemony, social, economic and cultural, within which it operates at the present time. (Foucault 1972 p.133)

Giroux's critical pedagogy was inspired by the work of Freire in promoting adult literacy within Latin American peasant communities. Freire's critical pedagogy (1972) is concerned with the development of "conscientização" usually translated as critical consciousness. Emancipation for Freire starts with the recognition of a system of oppressive relations, and one's own place in that system. The task of critical pedagogy is to bring members of an oppressed group to a critical consciousness of their situation as a starting point of their liberation. It is defined by a process in which individuals develop a deep awareness of the social structures that oppress them individually and collectively and result in resistance and counter-hegemony (Giroux 1983, p. 111). Foucault introduces the concept of subjugated knowledges that is relevant to the experiential knowledges and histories of the mad movement. He asserts that:

.....Subjugated knowledges are thus those blocs of historical knowledge which were present but disguised within the body of functionalist and systematising theory and which criticism - which obviously draws upon Scholarship-has been able to reveal. On the other hand, I believe that by subjugated knowledges one should understand something else, something which in a sense is altogether different, namely, a whole set of knowledges that have been disqualified as inadequate to their task or insufficiently elaborated: naive knowledges, located low down on the hierarchy, beneath the required level of cognition or scientificity. (Foucault 1972, p.82)

Subjugated knowledges resonate with the mad movement's experiences and activist endeavours. These endeavours aim to make visible the forbidden and excluded knowledges about the experiences of madness, psychiatrisation and oppression. Menzies et al (2013 p.14) assert that "the practitioners of Mad Studies are concerned with deploying counter-knowledge and subjugated knowledge as a strategy for contesting regimes of truth." In addition, Mad Studies has an aim to increase the credibility of mad knowledge by addressing the Epistemic Injustice experienced by the mad community.

A rights-based participatory approach to knowledge production of madness is also stressed by (2015). They assert that Fricker's philosophical concept of Epistemic Injustice in its form of testimonial injustice is worth exploring. Epistemic Injustice according to Russo and Beresford is useful to:

.....Offer good tools for re-assessing and changing knowledge production about madness and distress...Epistemic Injustice could thus be a very helpful framework for those faced with the uphill task of making the case for first-person knowledge of madness and distress. (Russo and Beresford, 2015, p.155)

Fricker defines Epistemic Injustices as twofold:

.....The overarching aim of Epistemic Injustice is to explore two kinds of dysfunction in our epistemic practices. The first occurs in testimonial transaction, when a speaker receives a deflated degree of credibility from a hearer owing to prejudice on the hearer's part..... but this is not all. The dysfunction of unduly deflated credibility may be not only an epistemic dysfunction; it may also be an ethical dysfunction. For the speaker who receives a prejudicially deflated degree of credibility from a hearer is thereby wronged—he is wronged specifically in his capacity as a knower. This idea of being wronged in one's capacity as a knower



constitutes my generic characterization of Epistemic Injustice. (Fricker 2008 p.69)

Testimonial Injustice is defined by Bondy (2010) as a type of Epistemic Injustice: “Testimonial Injustice involves the unwarranted denial of an individual’s credibility, which lowers a person’s status in the community of knowers” (p.266). Advancing survivor knowledge should be the primary concern of Mad Studies (Beresford 2016). Critical pedagogy projects, such as the MPHI course, are revealing and promoting subjugated experiential knowledge and challenging the dominant discourses about madness. It is a counter discourse that challenges notions of truth, knowledge production and credibility of knowledge. This PAR project is underpinned by philosophical and sociological theories of knowledge production advocated by the mad movement and influenced by philosophical and sociological theories of knowledge. The research position is underpinned by a position that user/survivor/mad experiential knowledge and histories are subjugated by more powerful discourses. Their position as knowers has reduced credibility and is subject to Epistemic Injustice in the form of Testimonial Injustice. CPAR recognises the knowledge of marginalised groups and is underpinned by promoting that knowledge to create counter discourses about the community (Fine 2008). This research aims to generate new knowledge about MPH and produce counter-knowledge about the experience and histories of madness by the mad community participating in this CPAR.

Canadian Mad Studies scholars, LeBlanc and Kinsella (2016), have added to this literature with a critique of sanism, Epistemic Injustice and the implications for knowledge generation. They assert that sanism marginalizes the knowledges of mad people. Mad epistemological perspectives of producing counter-knowledge are required as actions of epistemic resistance by the mad community. Challenging sanism within society and its institutions is a core aim of Mad Studies. Sanism is a term that was defined by Birnbaum (1960) and advanced by Perlin (1993). It describes the systematic discrimination and oppression of people who have been diagnosed and psychiatrised. Chamberlain (1990) coined the term ‘mentalism’ that is

frequently and interchangeably used with sanism. Poole and Ward (2013) assert that sanism is a devastating form of oppression that asserts a binary separation of those deemed to be normal, healthy and capable and those who are sick, incapable and disabled within society. Sanism results in stigma discrimination and oppression of mad-identified people. Cheung (2015) asserts that we need to name sanism:

“This void in our everyday terminology is telling: it implies that the oppression of people with mental illness face is so commonplace and routine that it doesn’t merit its own label. I submit that until we name it, we can’t effectively discuss it, and the absence of this name makes it easy for many of us to ignore it or deny its existence”

Cheung (2015) advocates embracing the use of sanism in our everyday language lets us better acknowledge the many parallels between it and other forms of discrimination or isms. In its critique, Mad Studies challenges the binarism of a world where there are those who are normal, healthy and capable and those who are not. Sanism is rarely discussed in the academy (Poole and Ward 2013). Sanism is perpetuated by society’s institutions and practices. Finkler (2013) critiques the presence of sanism in the language of housing law which impacts on survivors and housing practices in Ontario. Poole et al. (2012) critique the sanist culture of social work education. They promote an anti-sanist praxis which should include the intersectional analysis of sanism, racism and heterosexism. Challenging the hegemony of biomedical psychiatry, its reductionist medicalised discourse, sanist practices and its “psy violence” is a dominant position in relation to the aims of Mad Studies.

Russo and Sweeney (2016) offer a critique of the dominant biomedical discourse and the dominant hegemony of the “psy complex”. They promote alternatives to psychiatry’s dominance that is centred on the inclusion of survivor knowledge and the experiences of madness and distress. Mad Studies is grounded in the knowledge of those with the lived experience of psychiatrisation and takes a “subversive standpoint relative to the governing paradigm of psychiatric ‘science’” (Menzies et al. 2013, p. 11). The literature has a focus on challenging the dominant discourse of biomedical psychiatry

by providing a counter discourse. This discourse is being developed through the analysis, knowledge production and political action that promotes and celebrates survivor experiences, knowledges and acts of resistance (Menzies et al, 2013). Beresford defines the aims of Mad Studies as being a hopeful challenge to the dominance of the individualised medical model of mental illness. He asserts that: “Medicalized individual models of mental illness have dominated all aspects of madness and distress in the Western world since the 18<sup>th</sup>-century enlightenment” (Beresford, 2013, p. ix).

The critique of the dominant medicalised individual model of psychiatry has a long history. Foucault presents a critique of the discipline of psychiatry and questions its epistemological profile and practices:

.....If one takes a form of knowledge (savoir) like psychiatry, won't the question be much easier to resolve, since the epistemological profile of psychiatry is a low one and psychiatric practice is linked with a whole range of institutions, economic requirements and political issues of social regulation? Couldn't the interweaving of effects of power and knowledge be grasped with greater certainty in the case of a science as 'dubious' as psychiatry? (Foucault 1972, p.111)

Through the subversion of this dominant model, it is possible to provide alternative understandings and interpretations of madness and distress. Ingram highlights that this challenge to the dominant discourse is far reaching and is wider than psychiatry:

.....Giving the name Mad Studies to certain perspectives is intended to set a minimum threshold for academic investigations to be considered as offering radical critiques and alternatives to psychiatric, psychotherapeutic and psychological perspectives, whose pathologization of madness as mental illness entails wide-ranging negative social and political consequences. (Ingram 2008, p.1)

Menzies et al (2013) support Ingram's assertion that the pathologisation of mental distress reaches beyond psychiatry. LeFrançois et al. (2016) assert that the biomedical approach to experiences of distress continues to dominate mental health policy, practice and research. It is also dominant in related psychiatric disciplines of nursing, psychology and social work known as the “psy complex” (p.1). Menzies et al (2013, p.13) offer a clear aim for

Mad Studies in challenging the impacts of this powerful discourse and its affiliated disciplines. They assert that the primary aim of Mad Studies is to produce knowledge and political action dedicated to “the critique and transcendence of psy-centred ways of thinking, behaving, relating and being.” In relation to Mad Studies, the hegemony of the “psy complex” exerts this control through the promotion of its “regimes of truth”. This truth informs the practices by professionals and subsequently impacts on the experiences of those who come under its influence because of mental distress. The Mad Studies literature suggests that the “psy complex” informs and intersects with other neoliberal systems of oppression (LeFrançois 2013; Gorman & LeFrançois 2018).

Rose (2017) challenges the position within some Mad Studies literature that psychiatry is itself a homogeneous flawed field. The focus of scholars such as Burstow (2015) in advocating the dismantling of psychiatry contrasts to the Mad Studies scholars who highlight the need to creating alternative conceptualisations and practices. Rose (2017), however, is not arguing about the flaws within the psychiatry field. She is warning that a singular epistemological approach of Mad Studies, portraying psychiatry as the villain will limit proposing alternatives. She asserts the current crisis within psychiatry is an opportunity for developing alternative discourses created by Mad Studies. There is, however, an expansive critique that the aim of Mad Studies should be to challenge the dominant discourse and practices within psychiatry and the “psy complex”.

Beresford (2013, p. ix) states that, despite its dominance, many mental health service users report that its medical model is not only unhelpful but indeed damaging. The main critiques from Mad Studies literature assert that it has a reductionist philosophy that reduces complex human experiences and interactions with the world as individualised symptoms, genetic deficits and biological disorders. In this narrow analysis, it fails to address the social and trauma causational factors that lead to and perpetuate mental distress (Sweeney 2016). As a result, it responds with biological interventions,

predominantly medication despite service users valuing more social approaches (Beresford et al 2010; Beresford 2014). It utilises a reductionist classification system, The Diagnostic and Statistical Manual of Mental Disorders (DSM) or the International Statistical Classification of Diseases and Related Health Problems (ICD) that have both been critiqued as rigid, subjective with limited evidence to support their usefulness (Filson 2016).

The actions of the “psy complex” violate human rights, create inhumane conditions within psychiatric units and involve the abuse of legislative powers (Shimrat 2013). There is the use of excessive restraint and abuse of power by professionals within a risk adverse culture (Fabris 2016). The “psy” complex causes iatrogenic harm through “psy violence”. “Psy violence” is defined as the over-reliance on and excessive use of medication, and the infliction of trauma through the experiences and the long term physical and psychological impacts of treatments such as ECT (Weitz 2013) and medication. Mad Studies has as its aim, a collective exposing “psy violence” (LeFrançois et al. 2013; Russo & Sweeney, 2016. Liegghio (2013) critiques that under “psy” discourses and practices, psychiatrised people experience Epistemic Violence. This violence involves their disqualification as knowers, and being deemed to be both incompetent and dangerous. Their identities are pathologised and devalued, resulting in a denial of humanity and personhood. The “psy complex” is also critiqued as having an over-reliance on medication. This is part of a vested interest in promoting pharmaceuticals through the benefits of a co-dependent relationship with pharmaceutical companies that dominate health care agenda as described as “Big Pharma” (Law 2006). Beresford critiques its credibility, assertions and its questionable alliance to “Big Pharma” stating that “the psychiatric empire continues to grow, domestically and globally. Its ever-widening diagnostic categories, its increasing pretence of providing solutions to structural and social problems, and its unholy alliance with pharmaceutical corporations have all become defining features (Beresford 2013, p. ix).

Mad Studies is part of a mad movement that addresses the structures that oppress mad people and aims to reform and revolutionise the “psy complex” The “psy complex” produces poor personal, social and health outcomes for people who use mental health services despite large investment of money (O’Hagan 2016). The critique of the domination of the “psy complex” ideas, its practices and outcomes lead to assertions that Mad Studies must connect enquiry, intellectual activity and practice resulting in praxis. The processes involved in praxis are explored in more detail by Beresford (2013) who advocates for the importance of Mad Studies to result in praxis by asserting that Mad Studies must be aligned with practice to make up praxis. Praxis is defined by Freire (1972, p.99) as the “reflection and action upon the world in order to transform it”. Freire asserts that praxis is not only cerebral but it involves action and reflection. Praxis is generally defined as the point where academic activity is combined with practice to connect with action and change. Beresford asserts that Mad Studies is about activism that offers an alternative to psychiatry. The change required by activism is clearly articulated by Beresford who asserts “that change would be the opposition to psychiatry and a force for developing democratic and feasible alternatives to support our understandings of and responses to madness and distress at both individual and societal levels” (Beresford 2013, p. ix).

Critiquing the dominant discourse is advocated by the literature. Beresford (2016) asserts that there is a need for Mad Studies to create its own discourses, prioritise mad voices, develop forums and organisations to promote mad voices, develop knowledge about lived experience and develop survivor led research. This research has originated from a mad space and and prioritised the mad voices of the students.

There is a strong history of literature from user/survivor research internationally and theories of knowledge that have emerged from this work (Faulkner 2004, 2014; Rose 2003, 2008a, 2008b, 2017; and Beresford 2009; Beresford and Rose 2009; Sweeney 2009; Sweeney et al. 2009; Rose et al 2010; Sweeney and Russo 2016; Landry 2017).

User research has emerged from the service user movement but there remains a challenge of it being marginalised and receiving little funding (Rose and Beresford 2009; Beresford and Rose 2009). Rose (2008b) asserts that service user research challenges the discourse that the mad are not able to reason, be rational or engage in science. Rose asserts that the problems in the credibility of survivor knowledge lie in how it is evaluated by traditional research. Whilst the Cochrane hierarchy recognises expert evidence as the lowest form of evidence, the expert in question is not the service user. In her critique she asserts that unlike traditional research, user research has no pretence at neutrality and that the unspoken barrier is around perceptions about the capabilities of mad people. There are also issues of power and the perceptions of mainstream researchers not having a high regard for user research and not wanting to relinquish power in their domain (Rose 2008a).

Rose (2008a) asserts that there is a need for different standpoints and subsequently research methodologies and methods in mental health research. This does not exclude quantitative research, where appropriate. There is, however, a case to be made that qualitative research is frequently the most appropriate research to elicit the views of service users. She stresses, however, qualitative research is just as complex as quantitative research and this must be evidenced by doing it well. Rose concludes:

..... Service user produced knowledge – or “evidence” – uses different methods to mainstream research and consequently produces a different view of the world of mental health. Mainstream researchers need to look at this seriously and not dismiss it with broad and less than serious arguments. It is my view that to resolve such issues we should pay attention to the different epistemologies that underlie the fractures between mainstream and service user research. (Rose 2008 a, p.451)

User/survivor research has, however, grown in scale over the last thirty years and has created new knowledge for changing the mental health service, challenged traditional research and developed its own methods and approaches (Rose and Beresford 2009). Landry offers a barrier to survivor research asserting that: “People who have experienced the mental health system have historically been excluded from traditional forms of knowledge

production and are much less likely to receive or complete the expected academic training and credentials necessary to conduct and publish research studies” (Landry 2017, p.1438).

There have been explorations within the literature in relation to user/survivor research and Mad Studies (Beresford 2016; Sweeney 2016; Faulkner 2017). Beresford (2016) stresses the importance of building alliances with others to advance survivors’ rights and the importance of challenging traditional research. He asserts the need to recognise the importance of research and developing user/survivor research. Sweeney (2016) asserts that there is an intersection between Mad Studies and survivor research and they should foster a strong relationship in the development of critical and radical counter discourses. They provide a model for survivors generating knowledge beyond a consumerist service user involvement. She asserts survivor research offers key ethical principles to Mad Studies. Faulkner (2004, pp.3-8) outlines the underpinning principles of survivor research: clarity and transparency; empowerment; identity; commitment to change; equal opportunities; respect; openness about the theoretical underpinnings of the research and accountability. Sweeney asserts that: “we might consider adding “Participation/ownership: providing opportunities for research participants to become fully involved in the processes of the research, and in particular data interpretation, leading to a sense of research ownership” (2016, p. 49).

Mad Studies and survivor research both create radical new knowledges based on survivors’ own experiences and experiential knowledge (Sweeney 2016). Faulkner (2017) asserts that many survivor/ user researchers have demonstrated the value and the benefits gained by reducing the distance and power between the researcher and the researched. She advocates developing a more authentic connection with research participants.

This CPAR aimed to include a community of user/survivor/mad MPHl students in developing research about their experiences of madness and the MPHl course. It aimed to involve the students in every aspect of the



research, including analysis and dissemination. It aimed to generate knowledge and to work in partnership with academic partners to create knowledge and collaboratively disseminate that knowledge through conference presentations and publications.

There is a diversity of user/survivor-led alternatives to the “psy complex” within the literature. They include trauma-informed approaches (Filson 2016), peer support (Filson and Mead, 2016); and survivor led services (Staddon 2016; Rubinsztajn 2016; Bhakta 2016; Simpson 2016). Debates in the literature suggest the importance of alternative discourses, approaches and services to its domination. They warn that they tend to be co-opted, usurped and turned into “window dressing” (Brown and Stastny 2016). Examples include recovery (Morrow 2013, Mc Wade 2016), Recovery in the bin (2015) and peer support (Brown and Stastny 2016). Co-production, participation and partnership-working within it are frequently present in rhetoric but absent in reality (Roper 2016). It is outwith the remit of this review to critique all alternatives. There will be a focus on MPH as an alternative to the “psy complex”. In the second section of this review, there will be an exploration of co-option within academia and the last section of this review, there will be a critique of MPH.

This CPAR project has evolved from a long-standing partnership with the MPH course. This CPAR facilitates an alternative space to explore the experiences of the students on the course but also to explore the personal and collective experiences of madness. It aimed to explore the MPH course as facilitating politicised activist scholarship. There are varying positions in what the praxis of Mad Studies will focus on. These include challenging, reforming and creating alternatives to the hegemony and biomedical discourses of the “psy complex” to real alternatives that are peer-focussed, user-controlled and led, including services, research and scholarship. There is a position that psychiatry and the “psy complex” cannot be revolutionised or reformed and requires to be dismantled (Burstow 2014, 2015). There is agreement that revealing, challenging and eradicating sanism within wider

society and its institutions is part of the underpinning philosophy of Mad Studies. However, the Mad Studies literature also explores the experiences of intersectional discrimination and oppression. Psychiatry and the “psy complex” perpetuates a sanist culture that is also frequently experienced as racist (King, 2016), sexist (Staddon 2016), and homophobic (LeFrançois 2013, Diamond 2014). Mad Studies has been developed from the knowledge and experiences of allied social movements’ critical pedagogies such as Queer Studies, Disability Studies, Race Studies and Feminist/Women’s Studies (Menzies et al 2013). The intersectional history with allied social movements is widely reported and there is a debate within the literature about the benefits and challenges of an intersectional analysis, identity and resistances. LeFrançois (2012) asserts that “Mad Studies is reaping the benefits of new and ongoing partnerships with other marginalized groups. In learning from intersectional experiences of both oppression and resistance, through our identification with groups whose organized existence also threatens current forms of social dominance” (LeFrançois 2012, p.7)

The policy reports on the prevalence and intersectionality of people with mental health problems and other protected characteristics reveal a complex picture of multiple identities and oppression (MHF 2016 a, b, 2018; Scottish Government 2017a). This involves recognising the intersections of the multi-layered, multi-dimensional character of who we are in the world. Our experiences, opportunities, rights and health outcomes are also determined by the intersectionality of our multiple identities. However, there is a complex intersectional picture that acknowledges multiple identities that intersect around both advantage and disadvantage as reported by Gordon et al (2010) who assert:

.....All individuals are the sum of their personal characteristics ...the immediate social and physical environments that surround them, and the wider ecological, economic and political environments that in turn shape the immediate environment (Figure 1.1). Disadvantage in one respect may be offset by advantage in another, or compounded by further disadvantage. Personal financial resources can be a particularly powerful lever for reducing the impact of other disadvantages. (p.4)

In their exploration of the intersectionality of madness and disability and the oppressive impacts of intersectional identities, Jones and Kelly (2015) highlight the need to understand the interplay between the oppressive impacts of madness and other identities but also the diversity of those impacts. They assert: "A core tenet of intersectional theory is that confluences of social and biopolitical identity alter experiences not only in degree (that is additively) but what is more important, in kind" (p.50). Tam warns of the dangers of the current intersectional analysis of race and madness within the mad movement. She is critical of the additive model and comparison model of oppression that has been endemic in intersectional theory. In relation to madness and racism, intersectionality is used to analyse identity differences that interact with one another on different levels. This model ignores that identities and discourses are often inextricably bound in their formation and oppression from oppressive institutions and their processes (Tam 2013).

Within the Mad Studies literature there are debates that centre on the advantages and challenges of an intersectional analysis and intersectional resistance to oppression. Morris (2015), a disability researcher, asserts that there is unity in shared principles and goals within the mad movement and the People's Disability movement asserting: "Our perspectives may differ but two fundamental principles enable our common enterprise: our commitment to full human rights for all; and that there must be nothing about us without us" (p. xv).

Menzies et al (2013) assert Mad Studies has a role in supporting wider resistance struggles by informing social movements and their politics including promoting mad, race, disability and trans rights. The presence of an intersectional analysis within the mad movement is debated within the literature. In her critical ethnographic critique of the Toronto community of psychiatric survivor, mad and anti-psychiatry constituencies, Diamond (2013) asserts that there are tensions within the wider population on the experiences of psychiatrisation and how we conceptualise its oppression. Racialised

female perspectives revealed that their psychiatric oppression was intersected with experiences of racist and sexist violence and they did not identify with the survivor movement and its identity politics. She asserts that a mad-identity and a discourse that places mad at the centre can obscure other intersectional experiences and oppressive processes stating that “essentializing both mad discourse and psychiatric discourse has the potential to obscure how processes of racialization, gender, class, disability, sexuality, and other processes shape and define madness” (2013, p.71). Intersectional advocates assert that Mad Studies is at risk of being an ethnocentric discipline and discourse (Gorman 2013; Tam 2013; King 2016; LeFrançois 2016; Gorman and LeFrançois 2018).

LeFrançois (2016) asserts that Mad Studies needs to confront racism within the mad movement and also the privileging of white survivor contributions. She asserts that Mad Studies literature from survivors from the BAME communities and scholars’ highlights:

.....We are asked to think about and confront racism within and outside of psychiatry, including systemic whiteness not just within psy -systems but also within the mad movement itself, the privileging of white survivor contributions and erasure of cultural memory when it is not consistent with established white Western understandings. (p.vii)

LeFrançois and Gorman (2018) assert that there has always been a transnational, critical race and post-colonial understanding within Mad Studies. They cite Gorman (2013), Tam (2013) and Voronka (2013) as main contributors to the debate. They assert that Mad Studies should promote the racialised and colonised black experiences and histories within the psychiatric system. Challenge the targeting, over-representation and oppression within psychiatry. Those experiences are explored by King (2016), a Black African psychiatric survivor and researcher, who argues that post-colonial racism within white European psychiatry impacts negatively on the over diagnosis of schizophrenia and the treatment of black African men. He asserts that Western psychiatry needs to acknowledge that it has “invisible whiteness” demonstrated in Eurocentric and ethnocentric practices that have negative impacts on black men. Cultural misdiagnosis in relation to

mental health, race and culture reveals the emergence of a Eurocentric construction of mental illness that is rarely analysed. There is evidence that supports there is an over-diagnosis of schizophrenia in Black African Caribbean men within the UK and that they are more likely to experience cultural insensitivity and racialised stereotyping of their mental distress within services (MHF 2016b, 2018).

Gorman adds to this debate, exploring the promises and hazards of “Mad Nationalism” resulting in the mad movement being articulated through identity politics. She argues that mad-identity within Mad Studies will be absorbed into white middle-class narratives of disability and articulated as a position of privilege. The uncovering of class and the cultural relations in which mad identities are formed, she asserts is a challenge to the movement. In addition, she asserts that “identarian origin” stories have been widely critiqued in other social movements’ pedagogies such as gender and sexuality studies. They have led to multiple distortions within the Disability Rights Movement and Disability Studies. Gorman highlights the dangers of an identity-based mad movement that produces an essentialist, distorted white, westernised, middle-class discourse. She urges a refusal of the separation of mad-identity and critical mad politics and urges a connection of the struggles of madness, class, race and colonialism within racialised communities (Gorman 2013). Mad Studies has begun to include an intersectional analysis of madness but Mad Studies scholars assert that intersectionality needs to be expanded and embedded within the discipline (LeFrançois 2013; Gorman 2013; King 2016; LeFrançois and Gorman 2018).

In relation to this CPAR, the participants and partners are predominantly white women. There are a diversity of sexual orientations, disability, age and class within the research. However, an intersectional analysis of the course and this research are important. Mad intersectional scholars assert that there is a pervasiveness of whiteness (LeFrançois 2013) and the invisibility of whiteness (King 2016). They assert there is a need to embed sane and white privilege within the curriculum and research to address racialisation within

universities (Wolframe 2013). These issues need to be explored and addressed within Mad Studies.

There is a long history of disabled people and user/survivors being described under the identity of disabled in legislation and policy. There is also a history of collective struggle, with both movements benefitting from these developments. However, there are challenges in relation to the application of policies and in the identities, they define for user/survivors (Spandler and Anderson 2015; Plumb 2015; Rusno and Shulkes). Russo and Shulkes (2015) identify three debates within the user/survivor/ mad movement as: a disabled identity, the structural classification of survivors as disabled and using disability frameworks for political organising and advocacy.

Spandler et al (2015) include the perspectives of mad and disability scholars and explore the debates of intersectionality, of identity and oppression. They highlight the alliances between both movements. The debates are explored by Sapey et al. (2015) who pose questions about the benefits and limitations of madness as a disabled identity. Plumb (2015) identifies as an activist within the survivor movement and an ally to the Disabled People's Movement. She supports alliances that use disability legislation or challenge it to ensure rights for both movements. However, she highlights identity issues that differentiate user/survivors and disabled people. Medical diagnosis that is challenged within the user movement is rarely challenged but critiqued in relation to its reach and interventions for disabled people. Impairment versus environment is an ongoing debate within the disability movement in relation to the social model. The Convention on the Rights of Persons with Disabilities (CRPD) includes people with mental health issues under the term "mental impairment". Plumb (2015) disputes psychological impairment as underlying her experiences. In addition, she challenges the narrow definition of environment under the social model of disability. This does not fully explore how the personal, social and cultural environment affects people psychosocially and their role in creating impairment and mental distress. Shulkes and Russo (2015) assert the right of people with

mental health issues to self-identity. They reject that there is free choice in accepting disabled as an official status of within a neoliberal ideology. They propose collective action with the disability movement.

The issues of intersectionality of identity and oppression of user/survivors and disabled people are highlighted by Beresford (2015). He asserts that they are both subject to discrimination and oppression. He argues that it is possible to respect differences whilst building alliances and solidarity to challenge these negative impacts. Beresford (2013) argues that, in its rejection of medicalised understandings of disability, the social model of disability could be helpful in creating a counter discourse to the dominant biomedical model:

.....A counter discourse which, like the social model of disability of the international disabled people's movement, does not seek accommodation or understanding of the dominant traditional medicalized understandings, but instead seeks to confront them head – on and provide alternatives that offer positive promise for the future. (Beresford 2013, p .x)

Beresford has dominated the literature with asserting a need to seek social alternatives to understandings of mental illness. Beresford et al. explored service users' responses to a social model of distress influenced by the social model of disability. They conclude:

.....As we have seen, while disabled people frequently find the social model of disability helpful and identify with it, mental health service users seem much less likely to feel it can be helpful for them and are also often reluctant to identify as disabled. (Beresford et al. 2010, p.31)

The literature is dominated by the debate of the relationship of a model of madness and distress. The critique centres on the core constructs of impairment and environment within the social model of disability. The issue of impairment continues to prove a fundamental challenge to this alliance. Those politically aligned with the user/survivor movement tend to reject medicalised categorisation of their distress and do not consider themselves to be psychologically impaired (Beresford et al 2010; Plumb 2015).

There is a separate debate about what an alliance between both movements would entail and what mad activism and disability activism might achieve (Beresford 2000, 2002, 2015; Anderson et al 2015; Spandler 2015; McKeown and Spandler 2015). The issue of impairment continues to prove a fundamental challenge to this alliance. Those politically aligned with the survivor movement tend to reject medicalised categorisation of their distress and do not consider themselves to be psychologically impaired.

The inclusion of Mad Studies in Disability Conferences (Lancaster Disability Studies Conference (2014) has started an important dialogue that has potential for an intersectional critical pedagogy. Castradole asserts that “critical pedagogy is missing Mad and disabled perspectives, which may inform and inspire new critical pedagogical approaches. In this way, better complex cartographies of mad pedagogies need to be collectively drawn” (Castradole 2017, p.61).

Beresford (2015) locates the development of Mad Studies within the discipline of Disability Studies and the recognition of “neurodiversity” within that discipline. Along with other Mad Studies scholars, he advocates for an inclusive approach to these allied studies. Neurodiversity and its exclusion from academia are explored by Mc Wade et al. who assert that “to date, academic activities around madness and neurological divergence have failed to include those with lived experience, who are frequently frozen out of the processes of knowledge production” (Mc Wade et al 2015, p.305).

Mc Wade et al (2015) urge the development of theoretical and conceptual tools within a partnership of a neurodiverse collective including disability Scholars. Gaby (2015) asserts that neurodiversity offers a bridge to unite the disabled peoples and survivor movement as this community have roots in both movements. The Neurodiversity movement is a more encompassing term that includes people with the experience of attention deficit hyperactivity disorder and autistic spectrum disorders.



Disability activists and trade union activists are promoting alliances and collective action (McKeown and Spandler 2015). The transgender community require the sanctioning of psychiatry to be allowed to live as their authentic gender. There is evidence of emerging alliances with the neurodiverse community as asserted by Mc Wade et al. state that “the intersections between neurodiversity and trans and queer identities are already being realised around the term ‘neuroqueer’” (2015, p. 307).

The experiences of disabled people and the Disability movement have offered opportunities in relation to the Social Model of Disability influencing a Social Model of Distress (Beresford et al 2010; Beresford; 2013, 2015) and in promoting collective resistance (Beresford 2015; McKeown and Spandler 2015; Anderson et al. 2015).

The debate within the literature is on how useful this model can be to service users/survivors. However, Oliver (2013), who created the Social Model of Disability (Oliver 1983), offers a thirty-year retrospective critique of the challenges, successes and current crisis and diminished impacts of this model. He espouses its achievements in creating a collective disability consciousness, identification and eradication of disabling barriers, changing media representation, promoting accessibility to transport and buildings, improved inclusion to Higher Education and the creation of disability discrimination legislation. However, he stresses that the constant critique of the Social Model of Disability regarding the perceived abandonment of the experiences of impairment and a failure to recognise the intersectionality of race, gender, sexuality and age has had negative outcomes for disabled people. He asserts:

.....The Disabled People’s movement that was once united around the barriers we had in common now faces deep divisions and has all but disappeared, leaving disabled people at the mercy of an ideologically driven government with no-one to defend us except the big charities who are driven by self-interest. As a consequence of this, most of the political campaigning that has taken place in defence of our benefits and services have forced disabled people back into the role of tragic victims of our impairments and has involved others undertaking special

pleading on our behalf. In fact, it has taken us back more than 30 years to the time before the social model came into existence.” (p.1026)

Oliver stresses the importance of intersectional analysis and highlights areas that have benefitted the user/survivor movement these include: benefits, legislation and improved access to Higher Education. Individual differences and histories need to be acknowledged and intersectionality is not unproblematic in relation to theories, policy and identity politics. However, as asserted by Oliver (2013), there is a neoliberal attack on the disabled including people experiencing mental distress. Intersectional collective action offers a real resistance to neoliberal attacks. Ballantyne et al (2019) assert that “within a neoliberal climate, collectivism and resistance have never been more critical and at the same time never so difficult to achieve” (in press).

Within the Feminist and Mad Studies literature, the intersectionality of madness and gender is explored. Burstow (2014) asserts feminists have argued that psychiatry is an institution of social control over women. Chessler asserts that “It is viewed as a tool that supports patriarchy by forcing women into roles of “good wives” and “good mothers” and by silencing their responses to violence and structural inequality” (Chessler 1972, p.197).

This is underpinned by an understanding of gender as being constructed in and by society and culture, and not merely as a result of nature and biology (Connell 2009). Chessler’s seminal book *Women and Madness* (1972) is credited as the as being the most influential in asserting that there was a higher standard or reason and normalcy applied to women than men (Menzies et al 2013). Unsurprisingly, psychiatry was deemed to be gendered in all of its thinking and processes. Menzies et al assert that “the psychiatrization process was profoundly gendered-biased in its premises and effects, and that the very constitution of sanity and “mental illness” in the late 20<sup>th</sup> century was anchored in the bedrock of male normativity (Menzies et al 2013, p.6).

Male normativity, misogyny and sexism and the abuse of male power within society results in the abuse of women. This is articulated by Feminist scholar Connell (2009) who asserts:

.....the harm of gender is first and foremost in the system of inequality in which women and girls are exploited, discredited and made vulnerable to abuse and attack. The still massive incidence of domestic violence, rape and child sexual abuse (mainly, though not exclusively, of girl children) is an easily recognisable marker of power and vulnerability. (p.143)

Mad Scholars have critiqued the relationship and history between madness, child sexual abuse, trauma, and gender (Diamond 2014; Wolframe 2013; Filson 2016; Rubinsztajn 2016). Diamond's critical ethnography revealed that the gendered nature of society and its social institutions are reflected within the current "psy complex" practices and in the historical abuse of girls and women within psychiatric institutions. Diamond cites one of her participants who asserts:

.....Psychiatry is where women end up after they have experienced other forms of violence.....abuse in the family, child abuse, spousal abuse, rape, other assaults... when they react... when they are not functioning in a way that makes others around them uncomfortable, they are sent to a doctor... they are drugged, shocked into submission until they learn to act in a way that is more comfortable to others. (Diamond 2014, p.197)

Rubinsztajn (2016) explores her work in setting up and running an organisation in Berlin over thirty years ago founded by cis gender women who identified as survivors of childhood sexual abuse. She highlights issues of survivors not being viewed as stable enough to talk about trauma and their opinions are undermined. They are viewed within psychiatry and anti-violence projects as "difficult women" and "personality disordered". She is critical of survivors having their experiences pathologized and overwritten. She asserts the dominance of the psychiatric discourse is permeating women's anti-violence services and resulting in: "they lose sight of the fact that these women's reactions and ways of being in the world make sense, and are understandable in the light of the violence they experienced, and are in no way symptoms of a disorder. (Rubinsztajn 2016, p.130)

Filson (2016) asserts the importance of trauma-informed approaches and relates this to her lived experience of trauma and the medicalisation of her distress. She advocates for trauma-informed approaches that understand the links between trauma and mental distress, and are committed to not retraumatising people who have a history of trauma-induced distress. One of the traumas being challenged within the “psy complex” is the reduction of traumatic childhoods and mental distress of women being to a deficit in personality namely the gendered diagnosis of “Borderline Personality Disorder” (BPD). There is an activist grass roots movement challenging the validity of this label and campaigning for its resistance, opposition and critique. The guide asserts the number one suggestion to avoid a diagnosis of ‘personality disorder’ is to “try not to be female (for bpd)” (BDPINTHEBIN 2016).

The pathologisation of sexual violence leads women to the “psy complex”. The historical abuse of women within Psychiatry has been critiqued by Mad Studies scholars (Diamond 2013, 2014: St-Amand and LeBlanc 2013).

The scholarly critique of madness and women has expanded to include the experiential critique through the narratives of women who have experienced violence and iatrogenesis as a result of psychiatrisation and its confinement. St-Amand and Le Blanc (2013) explore the written narratives of three women in asylums in Canada in the 19<sup>th</sup> century. Their experiences highlight the historical power of men to commit women. It also reflects the misogyny and oppression of a male dominated society in which psychiatry was an integral power. The negative attitudes to women and mental distress meant they were diagnosed with labels such as hysteria and experienced abuse within psychiatry. The fight for release and rights once discharged, including custody of children, illustrates the struggle for woman to challenge oppression within and outwith psychiatry. St-Amand and LeBlanc (2013) assert the three women were activists challenging a male dominated psychiatry and were pioneers of both the feminist movement and the mad movement. Feminist Scholars and Mad Studies scholars critique the

intersection of gender and madness and expose the gendered inequality and violence within society and the powerful institution of psychiatry. It is clear from the literature that madness is a gendered experience and the violence experienced by women in society is mirrored in the experiences of women within the “psy complex” in its categorisations, theorising, actions and “psy violence”. This, however, is not confined to women as gender and sexual orientation also have an intersectional relationship with madness.

There is a long history of the oppression and medicalisation, iatrogenesis and oppression within the “psy complex” of the Lesbian, Gay, Bisexual, Transgender (LGBT) community. There are also interconnections between the struggles and experiences of the LGBT community and the user/survivor/mad community. In 1968, the American Diagnostic and Statistical Manual of Mental Disorders (DSM-11) listed homosexuality as a mental disorder. In 1973, the term was removed but replaced by “sexual orientation disturbance” which was not totally removed until 1987. Meanwhile, the World Health Organization (WHO) only removed homosexuality from its International Statistical Classification of Diseases and Related Health Problems (ICD) with the publication of ICD-10 in 1992, although ICD-10 still carries the construct of “ego-dystonic sexual orientation” (Datta 2014).

From a Canadian survivor perspective, Starkman (2013) recognises the importance of the Gay Liberation Movement’s history of homosexuality being considered a psychiatric illness. He stresses that this is a useful focus for the mad community in critiquing the validity of the terms used to define their mental distress. Datta expands on the significance, for the mad community in the removal of homosexuality as a psychiatric illness. He asserts that of the removal of homosexuality as a diagnosis offers the mad movement the following reflections:

.....Diagnosis-making is a social act; the construct of illness and disorder, ‘mental’ or otherwise is a social one; the construct of illness has social consequences; and shifts in the concept and nature of

disorder reflect wider social, political and economic forces more than scientific advancement. (Datta 2014, p.1)

Daley (2013) offers an insider experience of the intersectionality of gender, sexuality and madness within psychiatry. In her qualitative research, she explored the experiences of queer women as they access and negotiate psychiatric services. She discusses a framework developed by queer women revealing women's bodies and the notion of space. Her research highlights the complexity of queer women negotiating in/visibility within these settings. The findings suggest that queer women have to negotiate the disclosure of their sexuality and face the barriers within a heteronormative culture within psychiatry. LeFrançois (2013) adds to this heteronormative debate through ethnographic research within Child and Adolescent Mental Health services (CAMS). The research explores the exercise and impact of heterosexist-infused power relations along with an analysis of the impact of multiple and intersecting subjectivities. These include those based on: age, psychiatrisation, gender and class. She asserts the importance of an intersectional analysis of multiple identities to politically and collectively subvert heteronormativity:

.....As such, the politics of the subversion of heteronormativity is a call to action, which may include an analysis of the intersection of multiple subjectivities in order to combat the normative structures that produce and maintain the binaries inherent within social injustices and privileges (p.10)

In qualitative interviews with a LGBTQT community about madness, disability and sexuality and gender in everyday life, Pilling (2013) adopted an intersectional analysis approach to examine participants' work lives. In considering the experiences of mad LGBTQT participants, he stresses the importance of keeping the intersectional character of identity and experience at the forefront of thinking about madness. Pickering argues that decisions about disclosure of mental health as an invisible identity caused distress to participants. It made it difficult for the participants to be perceived as 'authentically' or 'truly' disabled, and therefore entitled to access accommodations. In addition, disclosure of sexual orientation resulted in the

homophobia and/or transphobia at work. An intersectional analysis revealed that madness cannot be considered the only salient aspect of subject positions and that multiple identities operate together to shape experiences and oppression. Voronka and Fitzpatrick assert the importance of recognizing the intersectional experiences of Tran's people and madness in relation to the medicalisation, pathologisation of personhood, and the coercive power and control of psychiatry. They are critical of Gay activists who have not worked in solidarity with mad people and urge Tran's activists to recognize that psychiatrisation and oppression are shared experiences. A contextualized intersectional struggle is promoted they assert that "it is vital that we contextualize our struggle, not simply as one for "trans rights" but as part of the struggle of all the kinds of people whose bodies and psyches are deemed defective or deficient – not just mad people, but fat, disabled and racialized people too" (Voronka and Fitzpatrick 2016, p.1).

Wolframe provides an insider perspective that challenges the inclusion of intersectional identities within the academy. She asserts that as a student:

.....I always felt that my own knowledge and identity (as a woman, and as queer) had a place in the classroom; however, feminist and other critical theories, as they were taught to me, did not give me a way to talk about my experiences as a psychiatric patient (2013).

Wolframe (2013) asserts that she has privilege as an academic and advocates for an intersectional understanding of madness. She supports an inclusive approach to understanding and actively resisting other forms of oppression, which we may not have experienced. By embedding the awareness of sane privilege and other privileges within the curriculum, she asserts they will benefit user/survivor/mad communities and our allies. Spandler, a Mad Studies/ Disability Studies scholar, and Barker, a Queer Studies scholar (2016), explore the common ground between Mad and Queer Studies. They assert that: they both challenge existing binarism, critique normativities, and need to examine their own histories of inclusion and exclusion. They advocate that Mad/Queer scholars and activists would benefit from more dialogue with each other.

There are debates within the literature about mad and intersectional identities. There is recognition of the benefits in relation to rights. There are calls for an intersectional analysis of madness and the reclamation of excluded intersectional histories and narratives. There are narratives of abuse and oppression from the intersectional discrimination of sanism, disablism, sexism, racism, classism and homophobia within society and the “psy complex”. The importance of intersectional alliances is stressed in the resistance to oppression. There is also a position that advocates closer links with allied social movement pedagogies and intersectional Mad Studies education within the University.

### **2.3 Mad Studies and Academia**

The importance of allies to support from the periphery and bolster the knowledge of those deemed mad is also stressed (LeFrançois 2016). Russo and Beresford support the importance of allies working with survivors to advance their rights. They stresses the difference of “those allies that work with us as opposed to on us” (2015, p.154).

There is also a critique within the literature on survivor narratives, generated by professionals who are part of the “psy complex”. One of note is Miller’s (2017) critique of Hornstein’s (2009) monograph “Agnes’s Jacket: A Psychologist’s Search for the Meanings of Madness.” He critiques the limitations of an outside analysis of survivor narratives. This resonates with the underpinning philosophy of Mad Studies of the importance of having survivor generated narratives at its core. This research facilitated a survivor analysis of the data generated. This is discussed more fully in Chapter Three.

As asserted by Reaume (2006) and Reville (2013), the relationship between Mad Studies and MPH within academia offers opportunities for survivors. However, the academic context also raises challenges for survivor/ user projects and poses risks to Mad Studies generally. Reville (2013) previous roles and identities spanning over forty years include, politician, activist, consultant, researcher scholar and survivor, despite this long career he



explores the challenges of Mad Studies within the University. The challenges include ensuring that mad students are at the core of his courses and mad scholars continue teaching the MPH course. Reville identifies the financial exclusion of survivors as students within the University an important issue and outlines his efforts to address this problem by raising funds Reville highlights a financial barrier to the centrality of survivor lecturers in delivering Mad Studies within a University he states that “you can’t build a new field of enquiry on part-time labour nor can you rely on true believers like me to do it for free” (Reville 2013, p.179).

Within the University, Mad Studies offers counter discourses on the interpretations of mental illness. Locating this work within a University is not unproblematic and Mad Studies scholars and activists have recently critiqued the relationship of Mad Studies with academia. Russo and Beresford (2015) acknowledge the valuable accomplishments of non-survivor academics. LeFrançois stresses the importance of academic allies and a collective approach in promoting Mad Studies to ensure the inclusion and centrality of mad knowledge:

.....Mad Studies is not about separatism, empire building or marginalisation: nor is it about academic or professional elitism. Mad Studies centres the knowledges of those deemed mad, bolstered on the periphery by the important relationships, work and support of allies-or by those who comport themselves as mad-positive. (LeFrançois 2016, p.5)

Mad Scholars recognise the change in the inclusion of mad people’s narratives that have been emerging in policy and practice over the last decade. They also, however, point to new complexities for the mad-identified voices and narratives in academia in relation to ownership and colonisation by a more powerful partner. Russo and Beresford assert:

.....If the first problem was getting any kind of recognition for such narratives, then now this has begun to be achieved, it appears we may have moved on to a further stage when an additional issue emerges. This is how to ensure that they are not just colonised or reduced to a new area for academic activity – taken from the control of their own authors. (Russo and Beresford 2015, p.155)

Mad Studies scholars Russo and Beresford (2015) also question the equity of partnerships with academics and how this powerful partner can be inclusive of mad perspectives. They advocate for outsider perspectives to address Epistemic Injustice.

Doubt is expressed about the ability of academics to engage in collaborations and dialogue with user/survivors that lie outwith their traditional divided roles as researchers (Russo and Beresford 2015). Going further than engagement, they assert doubt over their role in facilitating change stating “we therefore doubt the overall capability to foster substantive changes within or outside academia” (p.154).

Costa et al elaborate on the issue of dialogue and lived experience narratives. They also elaborate on the negative experiences of how survivor narratives have been used within practice and the issue of ownership and appropriation for diverse agendas. They assert: “We often find ourselves giving not just our story but also the knowledge that has emerged from our experiences only to have it re-framed, serving various purposes and different agendas, and ultimately alienated from us (Costa et al 2012, p.86).

In the literature from Mad Studies scholars, there is a clear warning to those identified as mad about reclaiming their history and stories and viewing with suspicion those who want to capture them as a commodity. Costa et al assert that when revealing stories, the mad community should be clear in whose interest are mad stories being soliciting and for what purpose they state:

.....Those who reveal their stories to consider doing so in a way that is politically accountable and focused on social justice change. And through this small act of organizing resistance, we inform those that solicit stories that we are now asking, in whose interest? (Costa et al 2012, p.99)

A way forward for academics to promote mad people’s narratives would be to authenticate service user’s experiences through adding academic authority to give credence and legitimacy by Russo and Beresford:

.....Those who have been 'experts' here traditionally as researchers, academics, need to think through their role. Rather than making devalued groups' narratives merely another subject of their enquiries, or a new field under their direction, they have a chance to 'authenticate' service users' experience through adding their 'authority', helping to give it credence and legitimacy. (2015, p. 156)

Beresford and Russo (2016) expresses concern regarding the sustainability of Mad Studies comparing the development of other user/survivor developments of recovery and peer support. They assert Mad Studies faces further challenges associated with its academic context. Besides the typical detachment from real-life issues and individual competitiveness that academia is based in, even the academic initiatives claiming to value and include experiential knowledge can end up appropriating and colonising this knowledge within the neoliberal University.

This raises questions about the role and motivations of academics working with social movements such as the mad movement. Cresswell and Spandler focus on the role of academics with the psychiatric survivor movement and debate the definition of the engaged academic. They assert that to be an engaged academic is "a matter of 'responsibility' and politico-ethical stance.....and to be 'valued', academic engagement is ultimately contingent upon a dialogic and future-directed relation, which can only be an 'unsettled relation' with the movement itself (Cresswell and Spandler 2012, p.15).

McWade (2016) highlights her experiences of the disablist politics of invalidation within academia and advocates for the validation of mad people's claims and an understanding of what undermines their demands for justice. However, the importance of a mad-positive engaged academic (Cresswell and Spandler 2012) working with mad-identified scholars in promoting mad scholarship with the mad movement is also stressed (Church 2013b). The role of the engaged academic is political and involves knowing when to be present or when to be absent. As an academic ally, Church (2013b) explores this dilemma of visibility/Invisibility and the importance of relinquishing the pedagogical centre. As an academic promoting this work, she also stresses the importance seizing of the pedagogical centre to raise visibility within the

institution. This has been apparent in this CPAR when activist co-researchers have appropriately asserted when to include and exclude the academic partner in data collection and dissemination of the research. It has also been an area of debate about how best to raise visibility and prevent co-option.

Landry and Church (2016) expand on the role of the ally academic and suggest that, from an insider standpoint within a University, mad-positive practice would involve challenging sanist assumptions in policies. It would assume that all students are mad unless otherwise stated. The complexities of mad scholarship within a neoliberal University creates numerous challenges for both mad-identified scholars and mad-positive engaged academics. These include: institutionalised sanism (Landry and Church 2016), evidence-based teaching, managerialism, the organisational separation of instructors and subjects and the impediment of alliances with other social movement scholarship (Church 2015). Mad-identified scholars are frequently on insecure, low paid, part-time, sessional contracts (Reville 2013; Church 2013b) which reflects a neoliberal culture which values cost cutting over experiential expertise (Russo and Beresford 2015; McWade 2016).

Scandrett and Ballantyne (2019) assert that it is not insurmountable to effectively value, include and promote experiential knowledge to undermine a neoliberal academic context. Nevertheless, they also acknowledge this is associated with risk. In relation to the MPHI course, they assert:

.....It has raised some important questions about what constitutes a mad positive University, one which honours and legitimates hitherto silenced voices and privileges criteria of inclusion and recognition over selection and competition. In its small way, MPHI provides seeds of what might undermine the neoliberal University, especially through the public health recognition in the receipt of NHS funding. As such, however, it is also vulnerable to the progressive attack of neoliberalism in both universities and the health service, subject to severe austerity cuts and increasing marketisation. (Scandrett and Ballantyne 2019, p.11)

Mad Studies literature identifies critical pedagogy and historical memory work to promote historical consciousness linking the past to the present struggles

and to imagine alternative possibilities (Menzies et al 2013). MPH is a critical pedagogy that is underpinned by historical memory work of mad people. The focus of this CPAR is the MPH course with its origins in the MPH course created in Canada by mad scholars and academic partners. The experiences and critique of this Mad Studies project MPH by Mad Studies scholars will be explored in the next part of this review.

## **2.4 Mad People's History**

Geoffrey Reaume (2006) describes the first recorded Mad Studies course he delivered in Canada (2002) entitled "Mad People's History". Reaume is credited as the pioneer of the literature that falls under the umbrella term of (MPH). Reaume (2006, p.170) asserts that "psychiatry has traditionally been analysed from the perspectives of doctors and policy makers".

Reaume (2006) warns us that ignoring this Mad History is a form of historical disempowerment. MPH courses privilege the views and the history of mad people past and present. He stresses emphasis is on the uncelebrated and forgotten mad people and the importance of respecting the diversity of media that mad people have used to express their experiences and history. Reville led and expanded the Ryerson MPH work, for more than a decade from 2004. He collaborated with Jiji Voronka, Kathryn Church and guest lecturers. He identifies as a survivor and mad person. Reville (2013) explores his experiences delivering two MPH courses from 2004 to 2013, namely "Mad People's History" and "A History of Madness". Reville asserts: "If you do stuff, stuff happens" (p.174). This resonates with the author's experience of the connections that are formed when you establish a MPH course and which have led to this research. Reville stresses that there are opportunities as a mad person within academia in the advancement of mad students. He defines students as "high knowledge crazies." High knowledge crazies as "Mad-Identified people who are doing or have done post graduate work" (2013, p.170).

He also highlights the challenges of keeping mad-identified people at the core of MPH. He advocates bringing in survivors as teachers, sneaking survivors into the course and encouraging mad-identified people to enrol in courses. Reville advocates for survivor knowledge to be at the core of the curriculum, the importance of readings from survivor authors and sharing his mad story in his teaching. He stresses the creative opportunities generated into art by the students. Reville stresses the need for MPH to not be confined to the University but also to be out in the community. He highlights the importance of his partnership with Mad Studies scholar and mad-positive ally, Church in the development and survival of MPH at Ryerson University (Reville 2013).

Church has worked with survivors for more than two decades and been involved in Mad Studies in: generating, delivering and supporting the two Mad Studies courses delivered at Ryerson University as described by Reville (2013). Church (2013a) describes this work as “asserting mad knowledge” (p.181). She asserts that strategic curriculum development, taking risks with the curriculum and delivering MPH in a facilitative context are core to the longevity and success of MPH in Ryerson. The importance of location of the course and the connections to Toronto’s mad community are also stressed by Landry and Church (2016). The delivery of a MPH course offers an opportunity for students to come out as mad. It makes classrooms more accessible to psychiatric survivors and teaches students to think critically about madness (Landry and Church 2016).

Reaume’s (2016) work gave us a history, clear philosophy of MPH and details a syllabus to create the MPH course. MPH and MPH are Mad Studies projects that are challenging the exclusion of mad people’s experiences and voices and creating an ongoing history from a lived experience perspective. Although they are both MPH courses, we will differentiate them for the purposes of this thesis.

We were influenced by the experiences of Reaume, Reville, Church and Landry as they offer a critique of the challenges of delivering and evaluating

MPH courses. The MPHI course and this CPAR are aligned with Reville's advice to have survivor knowledge always at the core of this work. The experience of Church of locating MPH work in a facilitative context inspired me to locate the MPHI course and this research within both Health Sciences and Public Sociology. In relation to evaluating the MPHI course using CPAR, we were influenced by our Canadian allies to be mindful in defining the aims, methodology, methods and the actions of this research. As a Mad Studies project, this research focus is on: locating mad-identified people at its core and reclaiming the narratives, history and experiences of those labelled as mad. It is also generating and promoting Mad Peoples History and facilitating mad voice through the generation of written and visual histories of madness. Literature identifying the application of the Mad Studies discourse in practice is still emerging. This research hopes to add to this emerging literature through the knowledge generated by this CPAR.

## **2.5 Conclusion**

The literature suggests that there is diversity of perspectives about the aims, philosophy, actions and projects that come under the discipline of Mad Studies. We can conclude that Mad Studies has grown from allied social movements and that the ideas influencing its developments from the user/survivor movement and other critical pedagogies have been around for several decades. What we consider the emerging Mad Studies discipline has been developing in Canada and around the world over the last two decades. LeFrançois et al (2013) marked the first textbook to collate scholarship about the discipline. The literature suggests that it has emerged and been shaped by the wider mad movement and its critical allies. Mad Studies has been informed by the psychiatric user/survivor, critical psychiatry and anti-psychiatry movements. There is however a dearth of empirical research on this emerging discipline and this presented challenges for this review.

The mad movement has a long history and is inextricably grounded in the user/survivor movement. The mad movement is not a homogenous group and has many constituencies. There is a debate within the mad movement

about the need to prevent divisions that will dilute its aims and its emancipatory potential. There are debates about the use of the term mad within the literature. Whilst in academic and activist contexts, mad has been reclaimed and Mad Studies is becoming a recognised discipline, there is no consensus on its use by people who have experienced mental health issues as a positive individual, collective or political term.

What is central to Mad Studies is the importance of the mad community critiquing the dominant discourses on madness by creating its own discourses, spaces, partnerships and organisations. Its aims are to promote mad voices, develop knowledge about lived experience and develop survivor-led research, education and activism. Mad Studies should occur in many spaces within and outwith the academy but not without the mad community. At its analytic core Mad Studies should have mad people, mad issues and mad culture.

Mad Studies is an exercise in critical pedagogy focused on the radical co-production, circulation, and consumption of knowledge. The experiential knowledge of madness has been historically devalued, marginalised and excluded by the idea of expert knowledge. Mad experiential knowledge and histories are subjugated by more powerful discourses. Their position as knowers has reduced credibility and is subject to Epistemic Injustice, in the form of Testimonial Injustice. The dominant positivist analysis of bias and values reduce the credibility and legitimacy of survivor knowledge within research, policy, practice, research and education. The debate within Mad Studies is centred on the importance of sharing personal narratives versus the political purpose of narratives of madness. The focus of this discipline should be the promotion of survivor knowledges and voice that celebrate survivor experiences and acts of resistance. Mad Studies aims to challenge the hegemony of psychiatry, its reductionist biomedical discourses, practices and its sanist culture inflicting “psy violence”. Mad Studies is underpinned by critical theory and promotes a multi-vocal praxis and dialogue. Its actions aim



to promote alternatives to the “psy complex” hegemony, discourses and practices.

There is a diversity of user/survivor-led alternatives to the “psy complex” within the literature. They include trauma-informed approaches, peer support, survivor-led services, survivor-led research and Mad Studies courses within Universities. Debates within the literature suggest the importance of alternative discourses, approaches and services to its domination. They warn that they tend to be co-opted. The focus of Mad Studies extends beyond the “psy complex” to challenge sanism within society and all its institutions

The critical discourses of allied social movement scholars and activists have informed the development of Mad Studies. They share the intersectional experiences of oppression and the subsequent development of critical pedagogies and theories to challenge the dominant discourses and structures that create and maintain oppression. The intersectional history with allied social movements is widely reported and there is a debate within the literature about the benefits and challenges of an intersectional analysis, identity and resistances. There are calls for intersectional analysis of madness and the reclamation of excluded intersectional histories and narratives. There are narratives within the Mad Studies literature of abuse and oppression from the discrimination of; sanism, disablism, sexism, racism, colonialism, classism and homophobia within society and the “psy complex”. Intersectional narratives reveal “psy violence”, “Epistemic violence” and the violation of human rights. Practices are heteronormative, ethnocentric and gendered. There is a strong position advocating the importance of intersectional alliances in the resistance to oppression. Intersectional scholars advocate closer links with allied social movement pedagogies and intersectional Mad Studies education within the University. The literature is permeated with debates about the importance of alliances with other social movements, emphasising the need to respect difference whilst promoting alliances. Alliances would promote solidarity, collective resistance and action against the social structures, cultural norms and the social institutions that

result in oppression. The literature supports the importance of allies to support from the periphery and bolster the knowledge of those deemed mad working with survivors to advance their rights.

Mad Studies scholars and activists are critical and cautious of the relationships and partnerships between Universities and people who are mad-identified. These critiques assert that the narratives of mad-identified people are frequently excluded or colonised by academia and mad-identified people are frequently frozen out of the processes of knowledge production. Mad-identified academics and activists urge academics to open up the contribution of 'outsider' perspectives. They assert that academics have the opportunity to validate user/survivor 'experiences by using their authority, to legitimise their contributions and give credibility to their narratives and voices. Within the neoliberal University, Mad Studies must be vigilant to the appropriation and co-option of its activities. The debates within the literature raise key concerns of whether Mad Studies can be protected from being undermined, invalidated and subverted within academia. The literature asserts that survivor research within a University risks the academic commodification and colonisation of mad knowledge and making mad narratives an object of enquiry.

There is limited literature within Occupational Therapy on this emerging Mad Studies discourse. As part of the "psy complex", the author asserts that there is a need within Occupational Therapy education, practice and research to embed meaningful participation and partnership that include survivor narratives and knowledges of the lived experiences of madness, psychiatrisation and oppression

Mad Studies literature identifies an aim to engage in critical pedagogy and historical memory work. MPHI is a critical pedagogy that is underpinned by historical memory work of mad people within the University. MPHI originated from the MPH courses in Canada and the "Oor Mad History" research in Edinburgh. It is a Mad Studies course. MPHI promotes the creation of a learning community of mad-identified students, activists and scholars within a

University, to make sense of and deconstruct the dominant discourses of madness and their own histories of mental distress, psychiatrisation and oppression. MPHl is critical pedagogy that aims to raise consciousness and promote collective action that results in positive personal and social outcomes for the mad community. The MPH literature predominantly originates from Canada. CAPS and the user/survivor movement have guided both the co-production of the course and this research project.

Having delivered three MPHl courses at QMU, the anecdotal information from students and course evaluations indicated that there had been diverse experiences and impacts from participating in the course. The partners, students and author were invested in exploring the experiences and impacts of the course and ensuring the course survived. This research was designed mindful of the need to include, authenticate, validate and promote the narratives of mad-identified people and give voice to their everyday struggles. This Mad Studies research was informed and generated by mad-identified students on the MPHl course in partnership with a mad-positive academic who is the author of this thesis. This research was participatory, collaborative and involved knowledge production and praxis. Academics can ensure meaningful participation and prevent colonisation and marginalisation of collective knowledges by projects that include mad-identified people in that knowledge production.

Literature identifying the application of the Mad Studies discourse in practice such as the MPHl course is still emerging. There are clearly gaps in the literature on the experiences of being part of a MPHl course. The application and evaluation of MPH is emerging within the UK. This research aims to add to the Mad Studies literature and to promote the experiences and knowledges of user/survivor/mad students of a Mad Studies course MPHl at QMU. It also has a wider aim to promote MPHl as a political activist space

The inclusion of MPHl students in designing, carrying out the research and deciding on the methodology, methods, actions and dissemination of results was the starting point for this research. The next chapter will explore the

processes and experiences of designing and generating this research, and will critique the theoretical underpinnings and collective decisions that underpinned these processes.

### **3. Chapter Three: Research Strategy and Design**

As part of an overall qualitative research project that is focussed on the exploration of the subjective experiences of user/survivors who participated in the MPHI course, this chapter will take the form of a natural history of this research project. Traditionally research strategy and design chapters are generally formal and written in the third person as in the “author”. The decisions made about the design will be referred to as “we” or “our” to reflect the predominantly collaborative and participatory nature of this research. This chapter will explore the philosophy and values that underpin the choice of CPAR as the methodology and the links between the philosophy, methodology and methods used within this research. My own position and the position of the other partners of the research group will be discussed. This chapter will outline the methods used to generate and analyse data and the participatory and dialogical processes that were woven throughout this research.

I will firstly recap on the aims and objectives of this research and how they were decided, before proceeding to discuss our decision-making processes and experiences of producing this research. The research group was formed by the partners of the MPHI team who invited students to join us in creating research. Our experiences of the participatory and collaborate philosophy of the MPHI course led us to envisage research with users/survivor/mad and activist MPHI students as partners in every aspect of the research. We wished to collaboratively design, generate data, analyse data and disseminate our results. We collectively generated the aims of the research to explore the experiences and impacts of being a student on the MPHI course. We understood that MPHI as critical pedagogy had aimed to raise

consciousness, generate counter-knowledge and result in activism on a personal and/or collective level. We were interested in exploring the relationship between participating in the course, activism and emancipation. We also wanted to explore the experiences of madness, oppression and psychiatrisation through revisiting the Photovoice assignment produced on the course. From the beginning, our actions were agreed as having an aim to promote the mad experiences, histories and knowledges of the MPHl students.

### **3.1 Research Philosophy**

Research is underpinned by philosophical assumptions that consist of a world view about nature of reality (ontology), the theories of knowledge used by the researcher (epistemology), the values underpinning the research (axiology) and the methods used in the process (methodology); (Creswell 2013; Crotty 1998). Ontology is the study of being (Crotty 1998, p.10). Ontological assumptions are concerned with what constitutes reality, in other words what 'is'. However, different authors have diverse taxonomies in relation to research. Research paradigms encapsulate ontology and epistemology. In this work, we will refer to the philosophical stance as the research paradigm that includes the ontological and epistemological position. In addition, the axiology or values informing the methodology will be explored as aligning with both the philosophy and epistemological positions.

Researchers need to take a position regarding their perceptions of how things really are and how things really work. Research begins with a clear philosophy and the researchers own world view being made explicit as asserted by Cresswell:

.....The research design process in qualitative research begins with philosophical assumptions that the inquirers make in deciding to undertake a qualitative study. In addition, researchers bring their own worldviews, paradigms, or sets of beliefs to the research project, and these inform the conduct and writing of the qualitative study. (Cresswell 2013, p.15)

My own position within this work is as an academic who has worked for seven years, in the development of the MPHl course, with a community of user/survivor/mad/activist partners from CAPS. Over the last two years, four students from the cohorts have worked with two partners from CAPS and me, in designing and generating this research. I have been invited into this user/survivor/mad/activist community by the partners to co-create the course, and so to occupy an outsider position. Truman (2000) highlights the need to engage in dialogue about the issues that arise in the social relations of social movement research. These include questions around structural privilege and the role of the researcher in facilitating credibility, promoting skills and knowledge. There are also issues around the identity of the researcher in relation to the identities of the co-researchers. Negotiating these positions, identities and the privilege of not being mad-identified is explored more fully in the discussion section of Chapter Ten.

I would identify myself as a mad- positive researcher and an ally to mad-identified people. Reville (2013) defines a mad-positive person as someone who does not identify as mad but supports the goals of those who do. I relate to the description offered by Church in relation to being a researcher in this project. She asserts that “I speak only to research that is collaborative in production and to my positioning as an ally in the enquiry” (2015, p.268). The self-identities of my co-researchers are diverse and include: service user, psychiatric survivor, mad, having mental health issues, lived experience of mental health and activist. They adopt critical, anti-psychiatry and social justice positions to challenging oppression and promoting the emancipation of people with lived experience of mental health issues through activism. The diversity of identities and positions of the participants are explored more fully in the results and discussions sections of Chapter Ten.

We assert that a broad qualitative approach is best suited to the aims of this research. Qualitative research is a process investigating aspects of social phenomena that cannot easily be measured numerically (Sumner 2006). Lincoln et al (2011) assert that there are five research paradigms: positivism,

post positivism, critical, constructivism/interpretivist and participatory. This research is located within a within a critical paradigm.

Interpretivist research has been criticised for: being uncritical (Crotty 1998), ignoring power relations, not changing the social situation of participants, and creating knowledge that is devoid of emancipatory goals that gives voice to oppressed groups (Henn et al. 2009). Interpretive researchers produce theorized accounts from the participants voice but it is usually the researcher who leads the research design and the final interpretation and dissemination of the data (Scotland 2012). This leads us to a critical research paradigm. Critical research is also described as critical enquiry (Crotty 1998) and critical social enquiry (Carroll 2004) and critical social research (Henn et al 2009). It is directed at interrogating values and assumptions, exposing hegemony and injustice, challenging conventional social structures and engaging in social action (Crotty 1998, p. 157). Critical research views personal accounts of experience as informed by culture and need to be radically questioned (Crotty 1998). Critical research needs to take into account the historical, cultural social and political contexts which constrain human thought, experience and action. Carroll (2004) asserts that there is a symbiotic relationship between critical research and social movements. The PAR group are part of a user/survivor movement in Lothian and connected to the “Oor Mad History” project based at CAPS. This PAR is underpinned by interrogating the experiences of the MPHl students in relation to experiences of madness and the course and to produce actions that promote their perspectives and voice.

The aim of critical research is to emancipate the disempowered by individual and collective awareness that involves making people critically aware of their situation. It is frequently described as emancipatory research or anti-oppressive research (Kovach 2005). Critical research has emancipatory goals and claims empowerment for oppressed groups (Henn et al, 2009). Additionally, critical research must create an agenda for change or reform, enhancing the lives of the participants. Crotty (1998) suggests that “critical

enquiry remains a form of praxis - a search for knowledge, to be sure, but always emancipatory knowledge, knowledge in the context of action and the search for freedom” (p.159).

Sweeney (2009) asserts that user/survivor research’s broad aim is to employ critical and emancipatory methodologies and that critical research can best be understood in the context of empowerment.

### **3.1.1 Critical Epistemology and Methodology**

As a theory of knowledge, epistemology poses questions about who can be the knower, what is knowledge, and what is the relationship between knower and knowledge (Lincoln et al. 2011). This research is proposing that subjective experiential knowledge can count as useful social knowledge? Critical theory is a dominant epistemological foundation of critical research. Drawn from the heritage of Marxism, critical research is underpinned by critical theory and critical pedagogy that has its origins in the work of social movement critical scholars, predominantly Freire (1972) and Fals-Borda (1996). Critical Theory as a concept originated from The Frankfurt School Scholars: Horkheimer, Adorno, Marcuse, Fromm and others (Crotty 1998). Horkheimer (1937) explains the differences between traditional theory and critical theory is that, whilst traditional theory merely reflects the current situation critical theory seeks to change the situation.

Freire’s critical pedagogy (1972) is concerned with the development of *conscientizacao*, usually translated as "critical consciousness" that facilitates realising change through praxis, and reflection (Freire 1970, p. 48). Freire’s seminal work: “dialogical par excellence” (Freire 1972, p. 81) is central to working with excluded groups in society to ensure participation. The philosophy of this research is underpinned by Freire’s critical theory that emphasises conscientisation, praxis and dialogue. Barnard and Gerven assert that dialogue is a methodology that has emancipatory potential: “Thus, a critical dialogue between scholars and real world social movement activists



could truly advance the collective positions of all people working toward racial and social justice (Barnard and Gerven 2009, p.821).

Critical research should promote dialogical relations of equality between the researchers and participants. The orientation of this research is user/survivor participatory research. This focuses on challenging traditional positivist research relationships so that research “subjects” become research participants and partners, and develop a sense of ownership over the research (Sweeney, 2009, Russo and Sweeney 2016;). The critical theory with the most relevance to this project is standpoint theory that stresses that experience should be the starting point for knowledge production. Originating from feminist theory, it stresses the need to theorise the social world from the perspective of those experiencing it. In feminist standpoint theory, this focus is on women’s experiences. (Harding 2004). Rose (2017) asserts the need for collectively produced knowledge and looks to lessons from feminist standpoint theory for Mad Studies. According to Rose, Feminist Standpoint theory challenges notions of bias and over involvement of users (2017).”

.....I would argue that all research is biased. In fact, I would get rid of the term itself and replace it with a concept that comes from feminist research, that of “standpoint”. All research comes from a particular standpoint that infuses its epistemology, its methodology and the knowledge produced as a result (p.449).

She also argues that “knowledges which are self-reflectively partial and aware that they are grounded socially are therefore more transparent and ‘more objective”. (2017, p.784)

Faulkner (2017) supports Rose’s assertions and proposes that standpoint theory is important because it promotes:

.....Starting the process of inquiry from an ‘explicitly social location’, from the lived experience of those persons who have traditionally been excluded from knowledge production. Usually, in the case of feminist standpoint theory, this is women reclaiming the scientific ‘gaze’, as it were, from men. But the theory has been extended to other marginalised groups and communities seeking to produce, what Harding (1993) refers to as ‘a stronger objectivity’: the idea that

marginalised groups have a more complete knowledge because they have access to the mainstream discourse as well as their own.

The underpinning researcher's position is that user/survivors have useful experiential knowledge that has been subjugated and their credibility as knowers has been devalued resulting in Epistemic Injustice and oppression. This research also aims to challenge the subjugation of knowledge and Epistemic Injustice by making public the service user/survivor experiences of the MPHl, and also their wider concerns about oppression, through utilising CPAR to generate both knowledge and activist actions.

An important aspect of this critical research is the centrality of dialogue within the PAR group and peer dialogical approach throughout the research, in particular in the generation of data from peer interviews. Vaughn et al (2018) promote peer models within services and research. They assert that peers can be seen as more approachable and effective than professional researchers because they are viewed as being insiders with local knowledge. The standpoint of this research is that of user/survivor/mad MPHl students.

User/survivor research has a diversity of definitions within the literature including: survivor-controlled, survivor-led, user-led, user-controlled, 'user involvement' or peer research (Faulkner 2004). The debate within the literature is around the interpretation of what survivor involvement in research constitutes and thus determining its legitimacy as survivor led or controlled research. This research is collaborative as defined by Sweeney (2009) as a partnership between service users and academics. This research has a user focus and has been user-led in parts but not user- controlled as it has been part of a Doctoral thesis that has academic restrictions. The areas in which there was collaboration include: deciding on the research questions, designing the research, generating data, analysing data and deciding on and implementing actions. There have been clear user-led activities within the research of peer interviewing and dissemination of the research experience and data generated (Phillips et al. 2018). It has been on a continuum of collaboration, leadership and involvement that has not been linear.

The importance of survivor/ user research is clearly supported within the literature but it is not without challenges as well as opportunities. Sweeney (2009) and Faulkner (2016) identify that in collaborative research the dilemmas that occur are primarily around identity and power. There is scepticism about true partnership working and tokenistic user involvement (Rose 2003). There is also a body of knowledge that supports that collaborative research can produce strong research and be successful (Rose 2003; Rose and Beresford 2009; Sweeney 2016). These issues were apparent in this research and will be further explored within the reflections on the research in Chapter Ten. Sweeney (2009) suggests that positivist critiques have resulted in new research methodologies that have shaped service user/survivor research. These include action research, participatory research and emancipatory disability research.

Kindon et al (2010) describe PAR as an umbrella term that covers a variety of 'schools' of participatory approaches that are multidisciplinary and have numerous forms. These include: Action Research (AR), Participatory Research (PR), Community Based Participatory Research (CBPR), and Critical Participatory Action Research (CPAR), to name a few. Kindon et al (2010) et al stress that there are commonalities in these schools but their differences lie in their contexts, intellectual orientation and most importantly their world view and epistemology.

The literature frequently uses the terms Action research, PAR and CPAR interchangeably. Critically for this project, CPAR blends participatory action research and critical theory by advocating that the user/survivor MPHl students must be actively involved in all stages of the research process. It has a critical epistemology, is allied to social movements or marginalised groups within society, emphasises dialogue and praxis and proposes emancipatory outcomes. Sweeney (2009) critiques PAR as not having participation as an embedded approach, that it is only evident in degrees and that it is rarely achieved in every aspect of the research. In addition, in relation to challenging marginalisation, the focus is frequently on the micro

rather than macro level. Oliver (1997), a critical disability scholar, is critical of participatory approaches resulting in emancipation. He asserts that they rarely challenge existing power structures and the impact on disabled people's lives is negligible (p.26). He suggests the need for an emancipatory research paradigm that typically involves the researcher as a community member (Sweeney 2009). This research is exploring the relationship between the engagement in the course, activism and emancipation as possible outcomes. The emancipatory potential as a methodology requires critique.

### **3.1.2 Critical PAR**

CPAR has developed from the South American social movements of Freire (1972), Fals-Borda and Rahman (1991) Fals-Borda (1996). Freire (1972) developed community-based research to develop knowledge production and social transformation. Freire (1972) stresses the importance of research as engaged practice and an act of solidarity and support. He asserts that the ideology behind PAR is of more important than the methodology.

Freire (1972), Fals-Borda (1996), Hall, Swantz (2008) and Fine (2008) stress the importance of CPAR in critiquing where knowledge is produced and resides. In addition, they highlight importance of CPAR in facilitating the sharing of experiential knowledge and lived experience in order to create new knowledge for change. Wadsworth (2008) stresses the importance of PAR collaborations in understanding the context of where knowledge resides in order to effectively change and improve the problematic experiences of a group of people. Action for change is decided by the group. The critical scholars Brydon-Miller et al (2013) assert that PAR has a distinct focus on collaboration, political engagement and social justice. From a Disability/Mad Studies perspective, Church advocates for research that aligns with social movements and results in social change:

.....That point would hold true not just for teaching but for research as well. We push back against practices of inquiry that make disabled people the focus of inquiry: by category of body/mind, or by population.

Our aspiration is to stand with communities and with social movements in our attempts to know and to change the disadvantage people are compelled to live” (Church 2013b, p.2).

Wadsworth (1998) describes PAR as researchers and participants working together to examine a problematic situation and decide on action to change it for the better. The problematic situation that is the focus of this research is the lack of empirical knowledge about the relationship between engaging in the MPHl course, activism and emancipation. The secondary issue is addressing the subjugation and Epistemic Injustice of user/survivor experiential knowledge by making public their histories, knowledges and wider concerns of oppression. Beresford (2012) supports the need to use research to advance our understandings of our questions within the mad movement and the importance of generating evidence.

### **3.1.3 Values of CPAR**

Pain et al (2011) stresses the importance of the PAR group leading the knowledge production and deciding the actions about their issue. Durham University’s Ethical Guide for Participatory Research (2012) asserts that Participatory Research creates additional ethical challenges as the boundaries between researchers and participants become blurred. They advocate that Participatory Research needs to address additional ethical principles of: mutual respect, equality and inclusion, democratic participation, active learning, making a difference, collective action and personal integrity.

This research has developed out of a seven-year relationship with activist partners and students who created and participated in the MPHl course. Upholding these fundamental principles was reviewed throughout this process using critical reflexivity and dialogue. Issues that arose are discussed in more detail in Chapter Ten.

Reflecting on his PAR career, Fals-Borda (1996) offers guiding principles and values that underpin this research. These include: respecting and combining skills and knowledge with the researched community, working with them as full partners and researchers, not monopolizing knowledge generation or

arrogantly imposing your techniques, respecting and combining your skills with the knowledge of researched communities, being receptive to counter narratives, promoting counter-narratives and communicating results of PAR in an inclusive and understandable manner to the community (p.4). The importance of collaboration in knowledge production is expanded upon by Fals-Borda (1996) who asserts that: "PAR is a purposeful life-experience and commitment combining academic knowledge with common people's wisdom and know-how" (p.4).

This research is based on the premise that, as researchers, we do not give voice or empower people. We are allies to breaking down the barriers for people to find voice and have that voice listened to (Maguire 2000). Joseph Rowntree Foundation's guide on participation and empowerment (1994) emphasises the difference between power to and power over. They assert: that "people are empowered when they have the power to achieve what they want – their purpose" (p.2). This is in contrast to the disempowerment of survivors whose lived experience narratives have been commodified and colonised by people in positions of power (Costa et al 2014). The choice of a dialogical approach to CPAR methodology within this research, aimed to facilitate the voices and self-empowerment of the students.

The philosophical, epistemological perspectives and values of CPAR resonate with this research. As a methodology, CPAR seeks to make public the experiential knowledges and concerns of the user/survivor MPHl students and is committed to collaboration and the participation in every aspect of this research process. The congruence with the critical, participatory and political nature of the MPHl course made CPAR an inevitable choice of methodology to evaluate its impact. A dialogical approach permeates this research. Dialogue was the core of the PAR meetings to decide the aims, methodology, methods and actions of the research. Peer dialogue resulted in the generation and analysis of the data. The actions of the research were agreed through dialogue. The dissemination of the research results will be

negotiated through dialogue with the PAR group. Peer dialogical interviews were selected to generate the data.

### **3.2 Method of Data Generation**

Initially it was envisaged that the data would be generated by the user/survivor/mad students who were part of the PAR group. The PAR group agreed that it was important to include as many perspectives as possible. We, therefore, decided that the data generation should be extended beyond the participants own experience. We then decided we would invite the wider cohort of the MPHl students to take part in peer-led interviews.

From the beginning of our CPAR, we had agreed to explore the experiences and impacts of the course and the relationship to activism. We also aimed to promote the voices of the students in relation to their own mad history and identities. The actions were agreed as a means to promote the course as a politicized space for activist scholarship. An inclusive approach was extended to the actions of the CPAR. The wider MPHl student group and partners of the course were invited to create a Photovoice exhibition and a film. This would facilitate more students having voice to their lived experiences of madness and the MPHl course. Interviewing was agreed as the most appropriate method to explore the experiences of the MPHl students.

Qualitative methods were used to generate a depth of perspectives from the students. Cresswell (2013, p.40) suggests that the qualitative mode of research is one through which we aim to empower individuals to share their stories and hear their voices, thus minimising the power relationships that often exist between a researcher and the participants in a study. This research wished to explore the human experience of being identified as mad and being part of a MPHl course. Utilising CPAR and a dialogical approach we generated data through semi-structured interviews.

### 3.2.1 Interviews

Qualitative research in social research utilises in-depth interviews and participant observation (Henn et al 2009). The PAR group agreed that individual in-depth interviews would be the most appropriate method to generate data. The interviewers planned to ask a series of open ended questions to generate the participant's responses in their own words (Braun and Clarke 2013).

A semi-structured interview was agreed by the PAR group to generate data.

The areas on which we wanted to focus the questions were around identity, experiences and impacts of the course. We designed the interview schedule to provide deeper data on research questions (Appendix Two). Henn et al (2009) suggest that the use of structure and prompts allows the researcher and participant to enter into a dialogue about the topic being researched. We collectively designed the interview schedule (Appendix Two).

The initial dialogue about data generation agreed that all the members of the PAR group would facilitate the interviews. The students in the PAR group asserted that we might get more useful dialogue and data if the interviews were peer-led. This was agreed by the group. The interviews were peer-led by the PAR group and we matched the interviewees with the interviewers to create the most relaxed interactions. This was in relation to age, experiences and familiarity. We tried to match people who had not been in the same cohort. Braun and Clarke (2013) suggest that interviewing which matches the experiences of the researcher and participant can result in a more comfortable interview but that this doesn't exclude different world views about experience. Harding et al (2010) explore the experiences of peer interviews with homeless service users and assert: "While it remains 'untested', peer interviewing also appears to benefit those being interviewed, particularly regarding rapport. For these reasons, even taking into account the potential risks and uncertainties, peer interviewing is worthy of serious consideration when designing social research" (p.332).



Peer interviews are critiqued by Harding et al (2010) as: levelling power relations, shared language and non-judgemental approach. They also stress the issues in relation to exploitation of the peer interviewers, lack of training and support and issues of confidentiality. We addressed some of these issues by carefully planning the process. We invited an experienced qualitative researcher to deliver an experiential workshop on interviewing. We role-played interviewing. Initially the four students who volunteered to be part of the PAR group were individually interviewed by one fellow peer PAR group member.

We planned how we would provide support for the peer interviewers and participants. The five MPHl students who had volunteered as participants to were individually interviewed by one peer member of the PAR group. We organised these interviews on the same day. We had lunch to prepare the participants for the interviews and check informed consent. We had a debriefing session for both interviewers and participants after the interviews. There were a total of nine peer interviews. Vaughn et al assert the benefits of a peer model in research: “peer models conducted within a partner model versus an employment or advisory model may have a better chance of genuine engagement with peers contributing not only to rigorous scientific results but also translational community-level outcomes that matter to insiders” (Vaughn et al 2018, p.13).

### **Photo elicitation**

As one of the research questions focussed on generating data about the students own mad history and mad identities, we decided that photo elicitation would be used during the interviews to revisit the Photovoice assignment generated by the students on the course. An integral part of the course had been exploring individual and collective experiences of madness. We were interested in the importance of this method to the MPHl students. This would not be analysed but used as a prompt to explore the students' experiences of using this method on the course and also to explore their own mad histories and experiences.

Weber (2008) suggests that images can be produced by participants as data for the following reasons: to springboard theorising, to elicit or provoke other data, for feedback and documentation of the research process. They can also be used as a mode of interpretation and or representation (Prosser and Loxley 2008). The two forms of visual research most commonly used are: visual elicitation which involves using photos in a research interview (Rose 2016) and Photovoice (Wang and Burris 1997) involving participants creating photographic images. This research utilised visual elicitation using the Photovoice images generated on the course as part of the interviews.

### **3.3. Recruitment**

There were many stages in the recruitment process of this research they involved recruiting: the PAR group, additional students to be interviewed, and the participants for the actions of the research a Photovoice exhibition and film. Each stage of recruitment will be discussed separately and the participants and partners from CAPS introduced in the next section of this work.

#### **3.3.1 PAR Group**

All the MPHl students from the three cohorts who completed the course were invited by e-mail to be part of the PAR group to design and carry out the research (Appendix Three). Initially five students volunteered to be part of the PAR group but one dropped out. Three partners from CAPS who are our partners in the MPHl course volunteered to be part of the research. Two of the partners were also part of the planning group for MPHl course. One of the partners dropped out at the planning stage. This left us with a PAR group of seven: four students, two partners and me.

#### **Introducing the PAR group**

Collaborative Partners

CAPS Independent Advocacy has been a partner in this project that emerged from their work “Oor Mad History”. The community history worker who carried out that research was part of designing and delivering the MPHI course and this research. Another staff member from CAPS volunteered but dropped out of the research. A volunteer with CAPS with lived experience, who had been part of a collective completion of the MPH course at Ryerson online, volunteered to be part of the group. The following two tables introduce the PAR group.

Partners	Partner/Role
CAPS Independent Advocacy Community History worker	The community history worker who led the “Oor Mad History Project” volunteered to be part of the PAR group. Having been a partner in designing and delivering the MPHI courses, she was part of designing the research and some of the analysis. She does not identify as having lived experience of mental health issues but identifies as disabled and an activist
CAPS Volunteer	A volunteer from CAPS who was part of the planning of the MPHI course volunteered to be a member of the PAR group. She attended planning meetings, interviewed students and was part of some analysis. She identifies as having lived experience of mental health issues and an activist.

Table two: PAR Group Partners

Patricia	Patricia is a 59-year-old woman who completed the course in 2014. She has had experience of the mental health system since the age of 12. She reports childhood abuse that led her to being psychiatrised and was subjected to abuse in adult in patient services at the age of 14 by staff. Throughout her contact with psychiatry she has had numerous labels most prominently borderline personality disorder. She has been a survivor activist since the 1980s.
Shona	Shona is a 60-year-old woman who completed the course in 2015. She reports suffering from depression and anxiety since childhood and is still dealing with bereavement. She is retired but on completing the course identifies herself as someone with mental health issues.
Lorraine	Lorraine is a 39-year-old woman who completed the course in 2014. She has a history of mental distress and describes that she suffers from anxiety and depression. She is currently a Public Sociology student and works as a volunteer. She identifies herself following the course as a mad activist.
Eleanor	Eleanor is 39-year-old woman who completed the course in 2015. She reports having mental health issues since primary school. She has experienced Post Traumatic Stress Disorder (PTSD) and dropped out of college as a result. She identifies as a gay activist and as a mad activist. She is currently involved in training.

Table three: PAR Group MPHl students

### 3.3.2 Recruiting Participants for the Interviews

All the MPHl students from the three cohorts who completed the course were invited by e-mail to be part of the peer interviews (Appendix Four). Five students volunteered to be interviewed by peers, in addition to the four PAR students this brought the total interview participants to nine.

Martin	Martin is a 46-year-old man. He completed the course in 2014. He has had experiences of mental distress from childhood and reports suicidal ideation from the age of 14 and being diagnosed with bi-polar disorder at 17. He dropped out of University as a younger man. He has been diagnosed with ADHD and autism but identifies himself as neurodiverse activist.
Cleo	Cleo is a 46-year-old woman. She completed the course in 2016. She who was born in Africa and identifies herself as a mad black female artist. She has experienced mental distress throughout her life but in particular following bereavement. She runs classes for people who are in the BAME Community and is involved in arts activism.
Margaret	Margaret is a 57-year-old woman who completed the course in 2016. She identifies herself as a single woman who became ill and spent time in a psychiatric hospital. She volunteers.
Julie	Julie is a 48-year-old woman who completed the course in 2016. She has lived with social anxiety and depression for 20 years and was diagnosed four years ago with PTSD. She is currently working as a volunteer.
Sandra	Sandra is a 53-year-old woman who has a long history of mental distress including a diagnosis of borderline personality disorder and complex PTSD. She has been on psycho-active medications since 12 and experienced early childhood trauma. She has spent years in various psychiatric services. She has worked in peer support services and been involved in activism.

Table four: Introducing the students who were interviewed

### **3.4 Actions of the research**

#### **3.4.1 Photovoice Exhibition**

All the MPHl students from the three cohorts who completed the course and also the Photovoice assignment were invited by e-mail (Appendix Five) to be part of the exhibition. There were twenty-four students who took part in the exhibition to display their Photovoice image and narrative. Six students, two from the PAR group and four from the MPHl cohorts spoke at the launch of the exhibition along with one representative from the MPHl partnership. Many of the students from the wider cohorts spoke at the event and engaged in dialogue with the guests including the Scottish Mental Health Minister.

A sample of the Photovoice images that support the findings of the research are in (Appendix Six). Selective photographs from the launch of the exhibition are in (Appendix Seven).

#### **3.4.2 Film**

All the MPHl students from the three cohorts who completed the course were invited by e-mail to be part of the film (Appendix Eight). In addition, we agreed that the voices of the partners and teaching staff with lived experience should be included. The film volunteers consisted of: four PAR group students, one lecturer from the course with lived experience, three students from the course and me. This resulted in ten voices in the film, nine of whom had lived experience of mental health issues. Due to availability and time, the film was designed and edited by the PAR group but filmed by a student in film studies and me.

### 3.5. Research Process

#### 3.5.1 PAR Group Meetings

The PAR group met from April 2016 until March 2018. The group met on twenty-one occasions to: plan, design, generate and analyse data and to carry out the actions of the group of the production of an exhibition and film. The meetings were initially audio-recorded but due to the amount of data produced this was changed to minutes taken in a notebook and with actions and discussions recorded to bring to the next meeting. The group met over a two-year period with the PAR being involved at every stage of the project. The group however expressed no issues in the time intensity of this research. The following table shows the processes and timeline involved in designing and generating this research.

Date	Activity	Action
11/3/16	E-mail invite for participants PAR group	Recruitment
8/4 /16	First PAR training	Eurig/Elaine
29/4/16	PAR training opportunity circulated	Research Training
9/5/16	First PAR meeting	PAR, roles, agreements, timeline thoughts and concerns
1/7/16	PAR meeting	Research question/experiences of the course
7 /7/16	PAR Course Durham	Research Training
8/7/16	PAR Course Durham	Research Training
31/8/16	PAR meeting	Aims/Methodology and methods/ experiences of course and roles.
28/9/16	PAR meeting	Actions of Research
28/11/16	PAR meeting	Ethics
11/1/17	PAR meeting	Information sheets and consent forms discussed
3/2/17	PAR meeting	Research ethics application
2/3/17	Ethical approval granted	Sharing final application

20/3/17	PAR meeting	Interviewing, peer Interviews.
21/3/17	Interviewing workshop Interviews	Maria PAR group
23/3/17	Photovoice Exhibition	PAR action
27/3/17	PAR meeting	Peer Analysis PAR group Interviews/Dialogue
3/4/17	PAR meeting	Analysis PAR group Interviews/Dialogue
21/4/17	PAR Group	Peer interviews participants
27/4-14/8	Sick leave	
16/8/17	Researcher and film maker	Filming students and lecturers
21/8/17	Researcher and film maker	Filming students and lecturers
15/9/17	PAR Group	Analysis of second lot of interviews. First edit of the film
18/9/17	PAR Group	Analysis of second lot of interviews
22/9/17	PAR Group	Final analysis Input on analysis Maria
29/9/17	PAR Group	Final analysis
10/11/17	PAR Group	Celebration meal at the end of the research
<b>8/3/2018</b>	PAR group and participants	Second edit of the film

Table five: The PAR processes and timeline



There was visual and narrative data generated by the Photovoice exhibition and the film. This data was not analysed in this research but may be at a later stage. Some of the Photovoice images from the exhibition are available in (Appendix Six). The film is available in (Appendix Nine). The data generated from the interviews was analysed and the processes of that analysis will be critiqued in the next section of this work.

### 3.6 Data Analysis

The analysis of the data aligned with the methodology and methods of this research. Analysis was carried out in a collective, participatory and dialogical approach. This was aligned to Braun and Clarke's experiential research and interpretative analysis: "Qualitative analysis covers a spectrum from descriptive and exploratory through to more interrogative, theorised, interpretative analysis closely aligned with the experiential/critical orientation (Braun and Clarke 2013, p.173).

This analysis is aligned to Freire's generative thematic analysis. Freire asserts:

.....To investigate the generative theme is to investigate people's thinking about reality, and people's action upon reality, which is their praxis ...The more active an attitude men and women take in regard to their exploration of their thematics, the more they deepen their critical awareness of reality and, in spelling out those thematics, take possession of that reality (Freire 1970, p.106).

Thematic analysis is a method for identifying themes and patterns of meaning across data in relation to a research question. Braun and Clarke (2006) are critical of research "giving voice" to participants and also the idea of themes emerging from qualitative data analysis. They assert that themes originate in the heads of the researchers and this has to be acknowledged as the decisions that have been made about the data.

Data analysis was underpinned by a dialogical and participatory approach. There are debates within literature regarding participatory analysis and its challenges. Conolly (2008) highlights the lack of skills, awareness and

emotional maturity of the girls in her study to engage in participatory analysis. Other researchers suggest that the problem is not located within the individual but in the lack of training of the participants (Byrne et al 2009; Bourke 2009). Nind (2011) is an advocate of participatory analysis but stresses that its inclusion is a political and ethical choice as it lacks empirical evidence to support its effectiveness:

.....Yet in the absence of supporting empirical evidence the question of whether or not participatory approaches to data analysis are a 'good thing' remains one of political choice and the ethical allure endures. There is insufficient work to date to know what can be achieved in participatory analysis or what this means for the quality of the research, leaving researchers grappling with whether participation in analysis is an end in itself or a means to an end. (p.360)

The thematic analysis initially involved watching the individually filmed interviews. This was decided as an inclusive and collective method for analysing the data and meant we could stop the film and discuss thoroughly. This step constituted close familiarisation with the data, the creation of codes in each interview. The codes were descriptive comments focussing on the words presented by the participants. They were the building blocks of the analysis as an integral part the active process of identifying themes.

The PAR group collectively looked across each interview to identify patterns of meaning. Each question became the pillars of the interviews. Codes and themes were generated manually. It is important to note that the interpretation of this data was carried out by the PAR group including: the author, partners and students. We then looked at each pillar of the nine interviews and interpreted the meaning of the data. It is important to recognise that the interpretation of the data and themes were created by the researchers. The analysis was a dialogical, participatory, interpretive process reliant on what the researchers identified in the data. The dialogical process critiqued the meanings found in the data with the participants and researchers. The PAR group were able to contribute to the thematic analysis by being present in the analysis of their interviews. The five students who were not part of the PAR group were invited to watch the filmed interviews

and comment on the PAR group analysis. This went beyond member checking and involved a dialogical critique of the PAR group interpretations.

The nine interviews were then collectively analysed looking for lateral themes across the whole data set. Multiple themes were generated by the PAR group. We generated twenty themes from the interpretation of the whole data and had robust discussions about the themes and their definitions.

There are also assertions that what is also important is how the analysis matches the theoretical framework and methods of the research (Nind 2011).

We decided at the planning stage of this research that the students in the PAR group would be involved in all the stages of the research including analysis. We acknowledged that this would involve mentoring and training. We organised training in PAR, interviewing and analysis within this research. Cahill (2010) stresses that PAR analysis is based not only on the trends that are strong in the data, but the need to interrogate the differences. It was important to be aware of trends that were strong in the data but also the diversity of experiences and voices. Several levels of data analysis were carried out using generative thematic analysis. A dialogical and participatory approach was woven throughout all the stages of the analysis.

As part of the interviews the Photovoice assignment was revisited. The students interpreted this image as part of the interview. The images were not analysed by the PAR Group. We have included the image in the results section to illustrate the student's interpretation of the image.

The following table outlines the phases of the generative thematic analysis of the interviews.

Phase	Description of the process	Within this research
1. Familiarizing yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.	The PAR group collectively watched the videos of the nine interviews and individually noted ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code	Generated in dialogue with the PAR group. We looked at each interview and looked for areas of interest/codes across the five pillars of the individual interviews. This coding was words and concepts .The group identified and interpreted areas of interest (Appendix Ten).
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.	Conducted with the PAR group. We searched for themes under each pillar of the individual interviews using flip charts, post it notes and pens to look across the data. We interpreted the data collectively generating themes under each pillar of the interviews (Appendix Ten).
4. Reviewing themes:	<p>Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set</p> <p>(Level 2), generating a thematic 'map' of the analysis</p>	<p>Dialogical approach with all participants. The participants in the PAR group in dialogue discussed the codes and themes generated. (Level 1)</p> <p>We also looked across all the data generated under the pillars of all nine interviews to identify and</p>

		interpret the themes generated across all of the interviews and generated a table of all the themes (Table Seven).
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.	Partially conducted with the PAR group but completed by the author. We generated a lot of themes and subthemes under each pillar but had difficulty collectively organising them into overarching themes. I synthesised and organised the themes into overarching themes and subthemes. This involved decisions on the conceptualisation of themes generated.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.	I completed this final part of the analysis and writing up of the report for this thesis. This involved relating the themes to the literature and the research aims and questions. I asked the PAR group for their reflections on co-producing the research

Table six: Phases of thematic analysis (Braun and Clarke 2006)

The PAR group were present when their interviews were being analysed and contributed to highlighting areas of interest and the themes generated in their interviews and that of their peers in the PAR group. They collectively analysed the five additional student participant interviews. We had recorded the codes and the concepts around those codes were the initial themes and were identified on the flip chart. The process of analysis is presented in themed maps generated from the flip charts (Appendix ten). To present a clear picture of the data generated the maps have been collated into a table below:

<b>Pillar of the interview</b>	<b>Responses of interest(codes)</b>	<b>Sub codes/ themes</b>	<b>Initial themes</b>
<b>1.Motivation to attend the course</b>	(a) Sparked interest (b) Provocative (c) Different		1. Mad title of the course
	(a) Being in a University  (b) Free (c) Credits (d) No qualifications (e) required (f) Involvement of Caps  <b>(g) Lived experience of mental health issues</b>	(a) Status (a) Didn't have the opportunity to go due to my mental health   (f) Worked with them before  (g) Course for mad folk like me	2. Context and Requirements
	(a) Mental Health (b) My Diagnosis (c) Self (d) History of Mad people (e) History of Psychiatry (f) Different perspectives on Madness		<b>3.Knowledge</b>
	(a) Entry requirements lived experience <b>(b) Personal distress and history</b>	(b) Family member's committing suicide (b) Dealing with	<b>4.Lived Experience</b>

	(c) Step to recovery <b>(d) Anger</b>	own mental health (b) Wanted answers  (d) Psychiatric system  (d) Professionals	
<b>2.Reclaiming Mad</b>	<b>(a) Political</b> <b>(b) Activist Interruption</b> <b>(c) Empowering</b>		1.Positive
			2. Context dependent
	(a) Abusive (b) Accepts Sanism		3. Negative
<b>3.Experiences on the course</b>	(a) Too short  (b) Language too academic  (c) Lacking cultural perspective		1.Description of the course
	(a) Positive   (b) Negative	(a)Anger (a)Fear (a) <b>Safe</b> (a)Reflective  (b)Anger (b)Retraumatising (b)Shock	<b>2.Personal embodied</b>
	(a) Diversity <b>(b) Supported</b> <b>(c) Understood</b> (d) Heard <b>(e) Belonging</b> (f) Privileged (g) Energised <b>(h) Identity</b>  <b>(i) Connectedness</b>	       <b>(h)Parallels with gender identity</b>	<b>3.Collective</b>
<b>4.Photovoice/Mad History</b>			<b>1.Gender</b>
			<b>2.Abuse and Trauma</b>
			<b>3.Labelling, Identity and Stigma</b>
			<b>4.Exclusion</b>
	(a) Justice		<b>5.Struggle</b>

	(b) Survival	<b>(b)Experiences of madness</b> <b>(b)Psychiatric system</b>	
			<b>6.Culture and Transition</b>
<b>5.Impacts</b>	(a) Increased self confidence (b) Improved self esteem <b>(c) Finding individual voice</b> <b>(d) Identity change</b> (e) <b>Raised consciousness</b>		<b>1.Personal</b>
	<b>(a) Collective Consciousness</b> <b>(b) Empowerment</b> <b>(c) Advocacy</b>  <b>(d) Activism</b>	(c)Individual (c)Collective  (d)Individual (d)Collective	<b>2.Political</b>
	<b>(a) Support</b> <b>(b) Reciprocity</b> <b>(c) Belonging</b> <b>(d) Connectedness</b> <b>(e) Social Networks</b>		<b>3.Social</b>
	<b>(a) Employment</b> <b>(b) Higher Education</b> <b>(c) Teaching</b> <b>(d) Conference Presentations</b> <b>(e) Research</b>		<b>4.Occupational</b>

Table seven: Initial codes and themes under the pillars of the interviews

The PAR group attempted to organise the data analysis into clear overarching themes, themes and subthemes (Appendix Eleven) but we struggled to identify the organisation of the overarching themes and subthemes across the data set. We could see the relationships between them and broadly identified that: knowledge, lived experience, activism and social processes were dominant themes. The author synthesised and organised these themes into four overarching themes and subthemes and related the themes to the research questions combining them with appropriate extracts and photographs from the interviews. There were



decisions taken about the synthesis of the overarching themes that reflected our group discussions. There were decisions taken by the author on how to organise the themes and what constituted an overarching theme, theme and subtheme. This is reflected in the results chapters.

### **3.7 Ethical Considerations**

Ethics in relation to PAR research is defined by Banks and Armstrong as: “Ethics as a subject area traditionally covers topics such as the overall harms and benefits of research, the rights of participants to information, privacy, anonymity and the responsibilities of the researcher to act with integrity” (Banks and Armstrong 2012, p.5). Ethical approval was sought by the group and granted prior to the data generation phase of the research (Appendix Twelve).

#### **Autonomy**

Autonomy was a major consideration. The students were at all times voluntary participants in this process and were given written information sheets about the project, what it would entail and all of the data generation that they may be involved in and where this would be disseminated. The participants were informed that they could withdraw at any time from the PAR group, interviews, exhibition and film. Two people withdrew from the PAR group but all participants who volunteered for the Photovoice exhibition and film completed this part of the project.

#### **Informed Consent**

Each student who had completed the course was sent an e-mail outlining the research and the data generation activities planned (Appendices: Three, Four and Five). The students who volunteered were sent information sheets and consent forms to be completed before they participated. The students interviewed were talked through the process to check that they still gave consent.

Participation in the interviews was voluntary and prior informed consent was completed (Appendix Thirteen). Participation in the Photovoice exhibition was voluntary and prior informed consent was gained before it was launched (Appendix Fourteen). Participation in the film was voluntary and prior informed consent was gained before it was made (Appendix Fifteen).

### **Anonymity**

Anonymity was an interesting ethical issue for this project. Many of the students were activists or have become involved in activism since completing the MPHl course. Many were vocal about wanting to promote their experiences, histories and voice through all parts of the data generated. Anonymising names, images, narratives and being part of the film required individual approaches to all students regarding their wishes. The researcher e-mailed each student individually regarding anonymity.

The PAR group agreed that names of the participants from the data generated from the interviews would be changed on any reproduction of the written data. The students were informed of this and asked what information they wished to be used to identify them. The Photovoice images and narratives in the exhibition was a complicated process regarding anonymisation. Some students wished for only their image to be displayed, some wanted their image and narrative included and some wished no name at all, or an anonymised name, whilst others wanted full credit for their work. Some photographs produced were of the individual students' and clearly identified them, once the images had been produced for the exhibition these individuals were given the options of:

- Including it in the exhibition unaltered
- Including the image but manipulating it to anonymise it by shading of their face.
- Removing the image from the exhibition.

The students were all asked about the issue of anonymity of the visual data from the Photovoice exhibition and all agreed to have their images displayed. Putting names and narratives with their image produced individualised and diverse responses. In response to this a selection of images and no names or narratives are provided in (Appendix Six) to give an insight into the exhibition. Photographs of the PAR group and the speakers at the exhibition gave consent for these images to be reproduced. The film clearly identifies the participants and this was an informed activist activity.

### **Anonymity and Dissemination**

In visual methods, participants are frequently not informed where their images will be disseminated. It was important that consent therefore included information about the possible dissemination of the students' narratives and images. The images will not be used in additional exhibitions without providing information about the exhibition and seeking consent from the students. The images will be co-owned by the University, partners and participants. All parties must approve the re-use of the images in an exhibition. Some images the students chose were of artists work. They were therefore under copyright and permission had to be sought from the artist prior to the exhibition. The film identifies the students and they all agreed that their name would appear in this work. It was important however to discuss where the film would be shown. The PAR group and participants agreed that it would be used to promote the course with appropriate audiences. They did however not want it to go on social media. The film can be located in (Appendix Nine).

### **Confidentiality**

The PAR group agreed to confidentiality within our meetings and throughout our data generation with participants. This was important to build trust and safety within the group and the research. When there are long standing relationships with each other, peer work can throw up issues with confidentiality. We resolved issues within the group and with the participants

but had outside supports when required. Interview films and transcripts will be retained for five years in a locked cabinet. Consent forms will also be kept in a locked cabinet for twelve months after being signed. The Photovoice images and narratives and film will be kept as an ongoing history of the MPHI course. Participants will be informed and involved in any future dissemination outwith the consent they have given.

## **Safety**

It was not envisaged that engagement in research about their experiences of MPHI would be invasive. The students who volunteered to take part in this research have longstanding relationships with the researcher and the collaborative partners from CAPS. Most of the group are activists and have a lot of experience sharing their narratives to audiences. It was however envisaged that when revisiting the trauma of mental distress and psychiatrisation this can result in distress. We therefore included pre-briefing and de-briefing sessions incorporated in all aspects of the research process and in particular the data generation activities.

There was also peer support within the PAR group and with the students being interviewed. There was distress at times in the PAR group, in particular anger and sadness when discussing personal experiences. This project took two years to complete and safety was an important culture throughout with acceptance of distress and support offered by the entire group. The e-mails of the researcher and academic partner were given to all participants and ongoing contact was maintained throughout this research project by phone, e-mail and meeting up outside the PAR meetings. There is a continued relationship with the group and promoting the course and the dissemination of the research experiences and results are ongoing collaborations.

## **3.8 Trustworthiness of the Research**

Rose (2008a) asserts that research produced by user researchers are critiqued for being biased, anecdotal and having over-involvement. She

argues that all research is biased and is underpinned by a particular “standpoint”. There is however no debate that qualitative research has to be rigorous and trustworthy (Faulkner 2004; Rose 2008a; Sweeney 2009). In response to the charge of over- involvement Rose (2008a) asserts that in her experience, all researchers have an investment in their research and most a passion for it.

This research has a mad standpoint and explores the perspectives of the MPHI Students. Cook (2009) asserts that the rigour of PAR relates to process and interpretation. The processes of the PAR were guided by participation, collective decision making, democratic knowledge production and transparency. The realisation of our rigour in fulfilling this rigour is explored in Chapter Ten.

The interpretation of the data was interrogated by the PAR group throughout the analysis. The trustworthiness of the overarching themes synthesised by were checked against the themes generated by the PAR group. To ensure the trustworthiness of this research the PAR group that was predominantly survivor-led. This research engaged in a visual and dialogical approach to data generation. The interviews were filmed to ensure that the voices and experiences of the students would not be misinterpreted or misrepresented (Braun and Clarke 2013).

The generative thematic analysis of the interviews of the PAR group students was carried out with them present. The other five non-PAR group students were shown the film of their interviews and through dialogue they contributed to the analysis and interrogation of their voice and the analysis of the PAR group. This influenced the final analysis and at times corrected misinterpretation discussed in the results section. This process was carried out by the researcher, who wasn’t involved in the peer interviews, to add rigour. This was also important as the peer relationships may have been a barrier to challenging the analysis. The PAR group were involved and passionate about this work. They, however, generated both positive and negative experiences of being part of the MPHI course.

All the themes from the data were generated and interrogated by the PAR group and students. PAR meetings were recorded by audio and notes taken to record decisions and debates. I recorded my thoughts in a reflexive diary to identify the contextual and researcher standpoint that needs to be acknowledged as impacting on this work.

### **Critical Reflexivity**

I used a reflexive diary to record the impact of the context, identities and power on the research. Reflexivity is an effective way for the researcher to think critically about the conditions and context in which the research is undertaken as well as acknowledging their own position within the research to help the reader understand their perspective and to eliminate bias (O'Reilly 2012).

The issue of bias is contested in this CPAR research and we reject that bias is not something that can be eliminated in research (Rose 2008a). In this research, the researcher's position is informed by a social research lens where reflexivity was explored to highlight the researcher's influences and world views on the research. The benefits of reflexivity are defined by O'Reilly: "research is enhanced by acknowledgement that the social world, the academic world, and the personal world of the researcher are intermingled and co-created through the ongoing process of social life" (O'Reilly 2012, p. 521).

The reflexive data generated is explored in researcher reflections in Chapter Ten. Having outlined the methodology and methods, the next section will outline the recruitment of the students.

### **3.9 Limitations of the Research**

A representation of the experiences of the MPHl course and its relationship to activism and emancipation was generated from nine students. This might represent some students who already were activists. This is true in part with

many of the students identifying as activists. The findings indicate that the participants who had completed the course now described themselves as activists. Aligned with the MPHl course and the results of the research, this is a diverse account of journeys to activism that for some started before the course and after the course.

The experiences of all the mad activist lecturers and partners who have taught on the course were not explored in this research. This has resulted in the absence of those perspectives. Only students who have completed the Photovoice assignment have been included in the research excluding the voices of those who chose not to complete the assignment.

There has not been an analysis of the themes generated from the whole project including the actions. The Photovoice exhibition and the film were not analysed due to time constraints on this project. This would have provided multiple representations of the students' experiences of the course and their wider issues.

The perspectives of the five students (three men and two women) who dropped out of the three cohorts of MPHl were not included in this research. I e-mailed all five students to include their perspective. We had a response from one student stating: "I did take on the course. It must be at least 3 years ago now but had to withdraw early after just one class due to ill health" (Female MPHl student). I did have conversations with two of the students who dropped out of the course prior to them leaving. One male student found the course too political and one female student had a change in her social situation that made it difficult to continue. We had no reply from the other two male students who both dropped out after week one of the course.

Post-Doctoral work could consider the perspectives of the partners and the analysis of the narrative and visual data generated by the Photovoice exhibition and film.

### 3.10 Chapter Summary and Discussion

Mad Studies literature supports the need for survivor knowledge and research to challenge the dominant biomedical psychiatric discourse and the practices of the “psy complex”. O’ Hagan (2016) states that psychiatry needs an alternative vision where lived experience of mental distress is viewed as legitimate and has value and meaning. Faulkner (2016), a survivor researcher, outlines the issues of identity and power and defines service-user research as: consultation, collaboration or service- user controlled. To be truly collaborative the project must involve partnership and co-production of the research before the proposal has been submitted. She stresses the need to move from involvement in research projects to partnership and collaboration. Mad-identified students have collaborated to produce this research, generate data, analyse data and design actions to disseminate this data to promote this community’s voices and knowledges.

MPH is one discourse challenging the exclusion of mad people’s experiences and voices, and creating an ongoing history from a lived experience perspective. This Mad Studies research aimed to harness the expert and experiential knowledge of mad-identified students in designing and participating in research that generates survivor knowledge, promotes survivor voices and creates both a visual and written history of the experiences and impacts of being involved in MPH. There is currently a dearth of research on the experience of being part of this critical pedagogy.

There is currently no literature on the impacts of being a student of a MPH course within the UK. There are clearly gaps in the literature of an emerging area of scholarship. At its core the literature suggests that there is a need for knowledge production about the experience of madness from those who have experienced it. Universities can ensure meaningful participation and prevent colonisation and marginalisation of collective knowledge by projects that include mad-identified people in knowledge production.



Our experiences of the participatory and collaborate philosophy of the MPHl course led us to envisage research with users/survivor/mad MPHl students as partners in every aspect of the research. We wished to collaboratively design, generate data, analyse data and disseminate our results. We collectively generated the aims of the research to explore the experiences and impacts of being a student on the MPHl course. We understood that MPHl as critical pedagogy had aimed to raise consciousness, generate counter-knowledge and result in activism on a personal and/or collective level. We were interested in exploring the relationship between participating in the course, activism and emancipation. We also wanted to explore the experiences of madness, oppression and psychiatrisation through revisiting the Photovoice assignment produced on the course. From the beginning, our data generation and actions were agreed as having an aim to promote the mad experiences, histories and knowledges of the MPHl students.

There were challenges within this research design. Participation takes time. This research project took over two year's part time to complete. We debated: the aims of the research, ethics, the methods, the actions, and the dissemination of the results. We analysed the data within a participatory and dialogical approach, this involved numerous sessions. There was debate about the themes and the definition of themes. We were inclusive in our recruitment wanting to involve a wider range of experiences and voices. We were mindful of the values of PAR and making sure our processes were trustworthy. Involving all participants in exploring the analysis was more than member checking it was a critical dialogue. We were involved in training on PAR, interviewing and analysis. The rigour, values and the challenges of this PAR project are explored in more detail in Chapter Ten. Our motivation underpinning this research is captured by Campbell and Oliver (1996): "We approach the research task as activists trying to make sense of our actions, not as researchers trying to be where the action is" (p.24).

#### 4. Chapter Four: Findings

Having critiqued and reflected upon the overall design and the experience and choices that guided our research, I will now present the findings. The voices of the participants resulted in the generation of themes in this research. The themes were generated from dialogue through interviews that included using photo elicitation by revisiting the Photovoice image completed by the students whilst on the course. The findings of the research are presented in the following four chapters, each in turn covering the four overarching themes generated by the analysis of the data. The students' voices will be in italics to differentiate them from the quotes from the literature.

The four overarching themes, themes and subthemes do not represent the pillars of the analysis that were generated by the main research questions. They reflect the themes that were generated across all data from the nine interviews. There was, however, a relationship between themes and the overlap will be addressed in each chapter. The four chapters will report and critique the findings through a Mad Studies lens in a summary and discussion at the end of each chapter.

The four overarching themes of this research are represented in Figure 2 below:

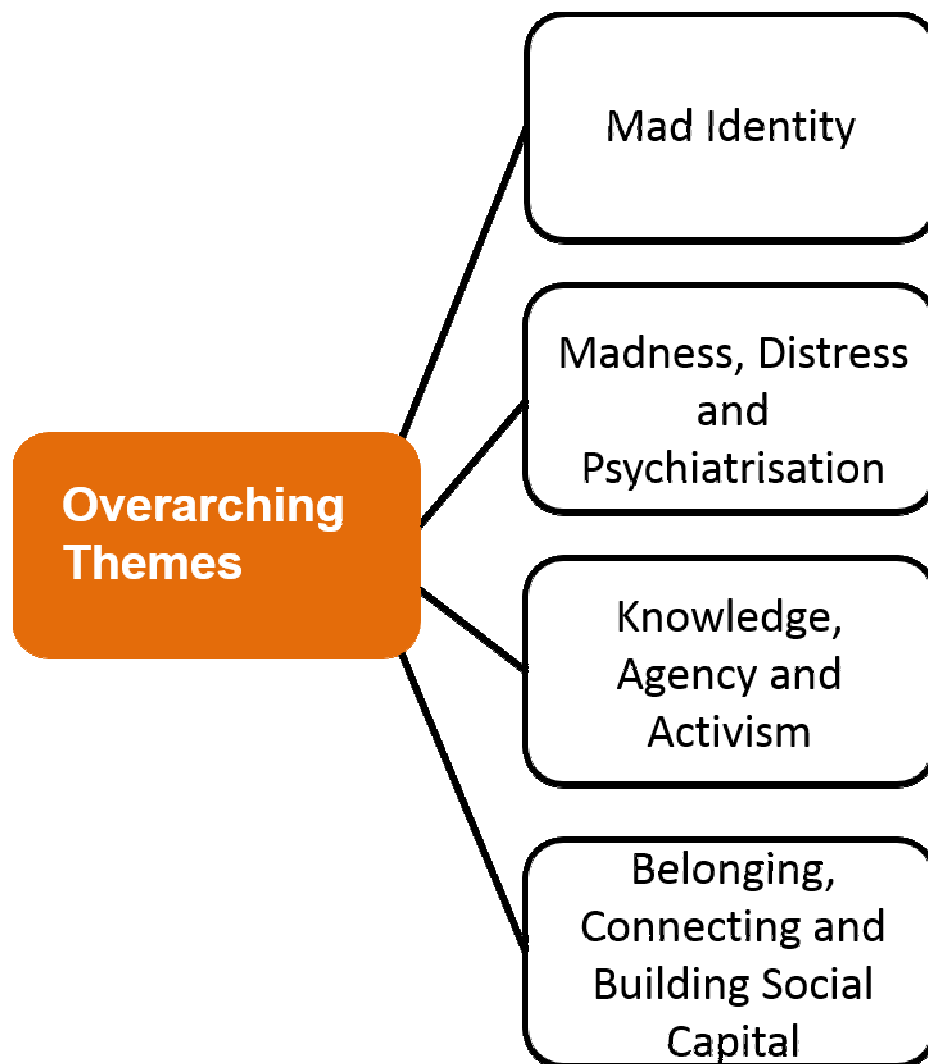


Figure 2: Overarching themes map

## 5. Chapter Five: Mad-identity

Mad-identity is the first of the four overarching themes identified in the analysis of the data. Mad-identity as a theme permeated the data. The students' motivations for coming on the course related to identity.

Lorraine: *it was for mad people like me*

The themes and subthemes identified under the overarching theme of mad identity are represented in Figure 3 below:

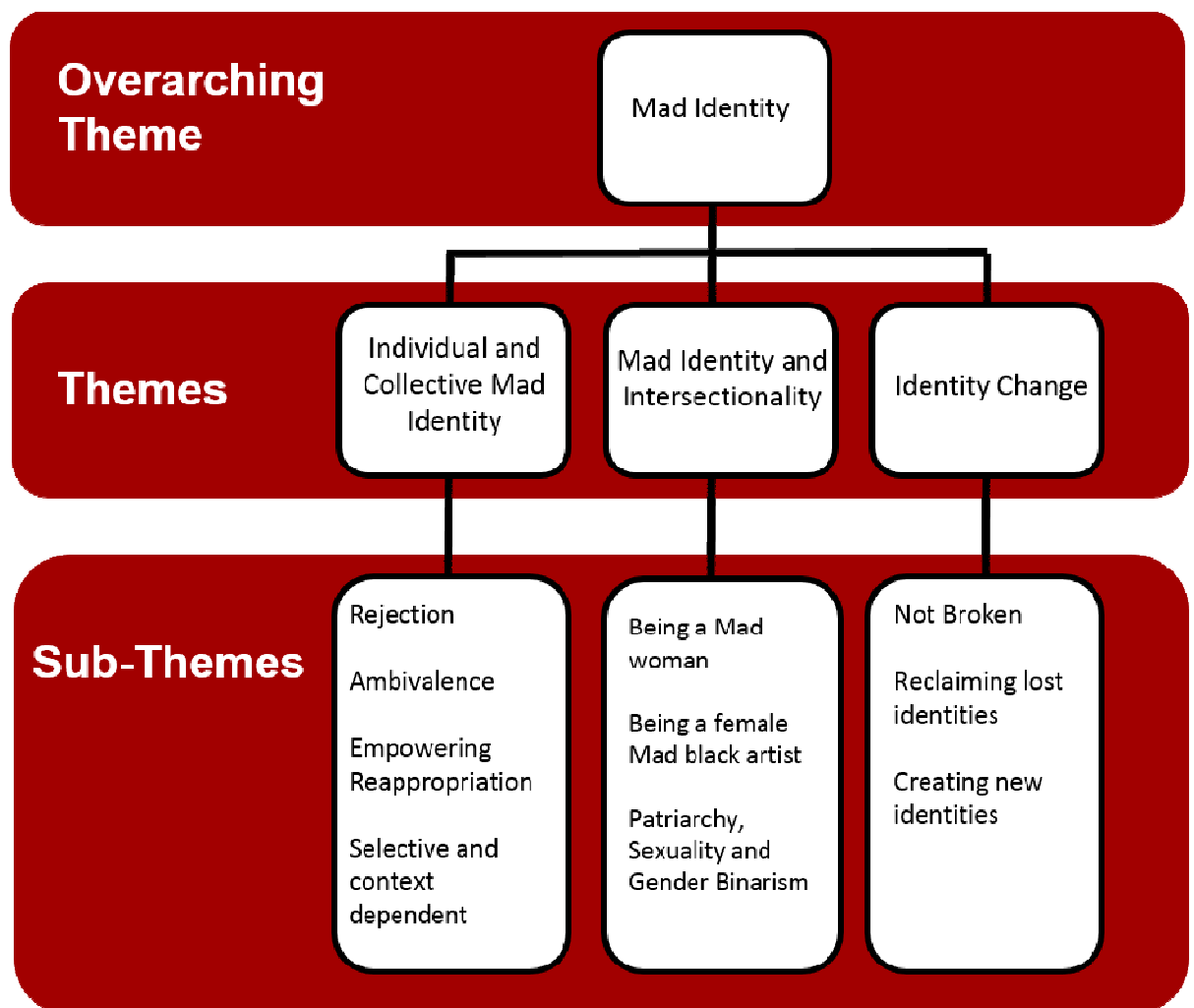


Figure 3: First overarching theme: mad-identity, themes and subthemes.

## 5.1 Individual and Collective Mad-Identity

Beresford et al (2010) research revealed diversity in adopting mad terminology related to identity. The research revealed that “the strongest personal reactions were to the words ‘mad’ and ‘madness’ “(p.21).

The first theme individual and collective mad-identity reflect the dichotomy of the students’ thoughts about reclaiming mad as a positive identity. This was influenced by whether they viewed mad as a personal identity or a collective identity. This choice was however not universally agreed as positive. There were differing views shared about reappropriating mad as an identity. They will be presented as the four subthemes of: rejection, ambivalence, empowering reappropriation and selective and context dependent.

### Rejection of Mad-Identity

The history of the word mad as a term of abuse made it difficult to reappropriate mad as a positive personal identity:

*Shona: I personally wouldn't use the word if I was speaking about my own mental health experience or someone else's mental health experience. Mad can cover a high spectrum of how people see you and you see yourself. I am still not mad.*

The students understood the challenges of reclaiming mad and the impact of its historical use as a term of abuse:

*Eleanor: It was interesting as it was controversial and caused a lot of people well... they were quite insulted by the course being called mad and stuff. That can all be down to the individual and how they feel about the word. If you've been called a mad bastard for your whole life by your family it's harder to figure out how to reclaim it.*

Students also rejected mad as a binary term that accepts that there is sanity:

*Martin: Personally, I don't like it. I like the duality of it between that anger and the dichotomy of it with sanity and sanism. I think is not something that I would use myself particularly as it implies that there is sanity as opposed to madness. I reject that and challenge sanism sometimes people are not sane not insane.*

Beresford et al (2010) revealed a rejection of mad by participants due to it being negative, labelling and stigmatising. There is a debate as to its usefulness (Beresford et al 2010, Burstow 2013) and the importance of its analysis and use (Burstow 2015). The students also expressed ambivalent feelings that echo the literature around how and why it is used.

### **Ambivalence**

The students reported ambivalent feelings about reclaiming mad dependent on how the term was used and by whom.

*Margaret: It's not always used in the right way. They call people mad. It can be hurtful when not used in the right way. I don't mind it; it can be helpful. It is overused and has multiple meanings. It bothers me when it is misused. I don't define myself as mad. I have had mental health issues.*

There was also ambivalence expressed about mad as another label:

*Sandra: I think it can be helpful depending on what company you are in to what you use. I probably don't use it as much now as I did two years ago. I don't mind identifying as mad. It doesn't bother me one way or another. I try not to label my identity at all so having even a word like mad to label myself I would find quite difficult to use.*

Beresford et al (2010) results echoed the students' ambivalent responses, with one participant asserting:

*.....Yes, but [the word mad] does describe certain things that happen to people. I don't agree with using it for a label, to say that somebody is mad. But if you use the word mad in amongst a group of people who haven't all experienced mental health problems, they might begin to understand what actually does happen to somebody who is having these problems, because in the first place they might be able to see in what ways it might be similar to their own experience (p.21).*

### **Empowering Reappropriation**

The students also viewed mad as positive, empowering and liberating:

*Sandra: Certainly, when I did the course in 2014, it was quite empowering that people were sitting and defining themselves as mad. I don't actually think I am mad.*

Lorraine: *I am very positive about it. I have used mad and madness verbally to people. It's kind of liberating. It's sort of a nice word. It can be a nice word.*

Mad as a positive identity was a rejection of the medical model:

Patricia: *For me, it was the fact that it was separating it from what is the very medical model of mental illness but is also around something which can be accepted as an identity which is a positive identity rather than see it as a deficit or illness. Being able to say this is me. I have these issues. I am mad. Accept me. This is who I am. Don't try and change me.*

Burstow (2013) asserts that language is important and both reclaimed and refusal terms challenge the hegemony of the psychiatric discourse and its terminology. The history of belong being part of other social movements that have reappropriated language was expressed. Beresford et al (2010) participants disagreed and did not view mad as offering an alternative understanding, but another negative way of expressing medicalised individual thinking

Being part of other social movements was important in the students' response to mad.

Eleanor: *I think the word mad is great. I think it is really important. I kind of understood a bit about that because I am gay. I know that gay folk have reclaimed words like poof and fag and dyke and so I know about that already. It's really important because it empowers people when a word is being used negatively then you can take it back and use. You take control of it and you have the power again that's really good.*

Martin: *It gave me great insight into the word mad and it destigmatised it a lot. I very much like the idea of mad pride and I can see how that has a lot of power and there's parallels between that and gay pride.*

Mad-identity was problematic for some students at a personal level but the distinction between mad as an individual identity and collective and political identity was clearly articulated.

Patricia: *Initially then I had some reservations about it because again in my head mad had always been a bit of a derogatory term but then as being part of that I realised that no, this was about us using a term which we had chosen.*

*Sandra: What I know about Mad Studies, it is important to use that word and identify as a group of people who have similar experiences. I think it's helpful to use the word that way.*

There are debates about the use of mad language but scholars are advocating the importance of its use in relation to a critical and political position (Fabris 2013) and its relationship to activism (Church 2013a). Some authors choose to capitalise “Mad” to differentiate it as critical and political (Fabris 2013). Mad is culturally a term of abuse towards people who have experienced mental illness/mental health problems/mental distress. The reappropriation of the term mad is a conscious political action by activists and scholars to reclaim a pejorative term and make it positive.

### **Selective and Context dependent**

There was, however, a perspective that whether mad was helpful or not depending on the context. It was acceptable within the mad community but the intention behind its use was stressed:

*Julie: You come on courses like this and realise it's not black and white. There's a lot of things about madness. We call each other mad but that's ok cause were all mad bairns. We kind of joke about it. It's ok in some contexts.*

*Eleanor: It's the whole thing.. it's important about language and how it is used. It's all about the motivation behind it. It depends on the context and how it's use. If somebody has problems with mad people it doesn't matter what words they used.*

Research carried out by Beresford et al reports a similar picture in relation to mad terminology but most of their participants felt that the term ‘distress’ was more helpful than ‘madness’. Participants felt that both madness and distress were seen to be a sign of weakness in society (Beresford et al 2010). Eleanor reflects the position of Burstow (2013) who asserts that what is important is the analysis and deployment of mad language. Their participants echoed the students’ perspectives in this research that there is a diversity of opinion and complex picture about mad language within the mad movement.



## 5.2 Mad-identity and Intersectionality

We had asked about mad language and identity but the data indicated that the course had facilitated a wider intersectional analysis of madness.

The second subtheme generated focused on the intersectionality of mad-identity with other oppressed identities. The students participating in the research consisted of eight women and one man. The subthemes generated were more expansive than women and madness and related to the intersectionality of mad-identity with gender, race and sexuality. We wanted to revisit the images and the students' interpretation of them to elicit deeper information about the usefulness of this method, the experiences and impacts of the course and reveal wider personal and collective experiences of madness. The first subtheme generated was being a mad woman.

### Being a mad woman

Mad-identity was related to the gendered social behaviours and expectations to which many women feel they are pressurised to conform. If they don't, their emotional responses are pathologised:

*Patricia: It's partly around in terms of reclaiming identity. In terms of, like, there's a sense of.. there's a real pressure now more than ever to fit in terms in all your relationships - be a good daughter a good mother, be a good wife, be a good worker, obey the rules, be perfect and work hard. You need to look pretty, behave nicely and don't be fucking angry - that's not acceptable.*

There is an intersectional analysis between gender and the experience of madness within Mad Studies and Feminist Studies. Psychiatry has a history of being gendered. Menzies et al assert:

*.....The psychiatrization process was profoundly gendered-biased in its premises and effects, and that the very constitution of sanity and "mental illness" in the late 20<sup>th</sup> century was anchored in the bedrock of male normativity. (Menzies et al 2013, p.6)*

Patricia related being a distressed woman had resulted in receiving a gendered psychiatric diagnosis of Borderline Personality Disorder (BPD). Patricia rejects this as an identity in favour of mad

Patricia: *One of the things in particular, reading the additional literature, I was interested in the identity side, in particular gender identity issues and about gender diagnosis as my diagnosis is a gendered diagnosis and is sexist and misogynistic. Even if I'm mad, it's ok. Don't call me PD. Over 75% of those diagnosed are women. The diagnosis within PD if you are a man you are more likely to be diagnosed as an antisocial personality disorder and if you are a woman it's BPD.*

One of the traumas being challenged within the “psy complex” is the reduction of women’s traumatic childhoods and mental distress being reduced to a deficit in personality, namely the gendered diagnosis of “Borderline Personality Disorder” (BPD). The next subtheme related to being a mad, black woman.

### **Being a Mad Black Female Artist**

The experiences of being a mad black woman in transition was described and visually represented by Cleo through her Photovoice image and narrative below:



Photograph 2: Reflecting on diverse cultures, thought processes and treatment of negative impulses

*Cleo: This Photovoice is where I am right now and about my mental health and my journey abroad in a cartoon. How do we keep our identity abroad? The mermaid represents healing through knowledge. I am trying to explore my journey as an immigrant and tie this into my cultural beliefs.*

The challenges of the intersectionality of culture and madness were explored by Cleo in relation to identity. In relation to her mad-identity she asserts:

*Cleo: I don't know about the word mad. It annoys some people. It doesn't annoy me. I have always been called a mad artist. It is quite odd. I find it quite nice to be a mad artist and I embrace it. Other people might find it derogatory or labelling. It is clear what you are studying. It is not cushioned with politically correct terms.*

MPHI was part of her journey of understanding mental distress but also her challenges managing the competing demands of protecting her cultural identity. Her identity was intersected with madness, race and gender and her occupation as an artist. Cleo did however highlight barriers to services in relation to race, cultural identity and beliefs within her community that are relevant to the MPHI course.

*Cleo: There are people who are unable to identify where to get help. You are resigning to Western ways of weakness. If you understood the patterns of behaviour in intersectionality they would cope better. From within the communities they need to let people in. A fear is that if I am identified then I will be locked up. That is what they have seen back home. They don't seek knowledge and support. I will pray to God if I am poor.*

Cleo's intersectional identity reflects the literature in relation to cultural fears about Westernised psychiatry in relation to race. She discussed racism generally in society and that the course had helped in her analyse and response to it:

*Cleo: There is the whole racist stuff and being able to deal with it. Racism is there. I try and understand racism as a lack of understanding and knowledge. I am not responding to things the way I used to. I learnt that from the course.*

The literature suggests racism within the “psy complex” and its institutions and practices. Mad Scholars’ analysis explores the intersectional experiences of race and madness within psychiatry and the mad movement.

It suggests there is a pervasiveness of whiteness (LeFrançois 2013), invisibility of whiteness (King 2016) and the need to embed sane and white privilege within the curriculum and research to address racialisation within universities (Wolframe 2013).

The last subtheme related to male gender and its constraints.

### **Patriarchy, Sexuality and Gender Binarism.**

There are complex debates within the feminist/queer literature on gender/sexuality and the problems of viewing them as binary and fixed. Butler (1990) suggests that gender is socially constructed and that there are problems with viewing gender and sexuality as fixed and binary.

Martin shared that the course had created a space for exploring intersectionality that had challenged his ideas about gender binarism and his own gendered identity and sexuality. This is visually represented by his Photovoice image and his interpretation of the image:



Photograph 3: The Big Chair

Martin: *The chair was given to me by my family. It was part of a set of five. It was the big chair with the arms. It symbolised the patriarchal nature of my family. I had taken the arms off with a hammer to make it more equal with the others. It was a really, really empowering moment for me to do that.*

Martin: *I couldn't imagine gender change, couldn't explore my own sexuality".*

Photovoice had facilitated an analysis of his gender and sexuality in relation to the influence of a patriarchal childhood. The intersectional Mad and Queer Studies literature suggests a heteronormative culture within society and psychiatry (Daley 2013, LeFrançois 2013). Martin suggests that the MPHl course facilitated an analysis and critique of gender binarism and the impact of society's heteronormative culture on his identities. The third theme generated was the impact of the course on changing self-identity.

### **5.3. Identity Change**

The first change that the students shared was that they no longer individualised the experience of madness. They rejected the biomedical model's interpretation of their distress as being diseased or broken and therefore needing to be fixed. The dominant medical model within psychiatry has a reductionist philosophy. It reduces complex human experiences and interactions as individualised symptoms, genetic deficits and biological disorders. In this narrow analysis, it fails to address the social and traumatic causational factors that lead to and perpetuate mental distress (Sweeney 2016). This led to a description of not being broken.

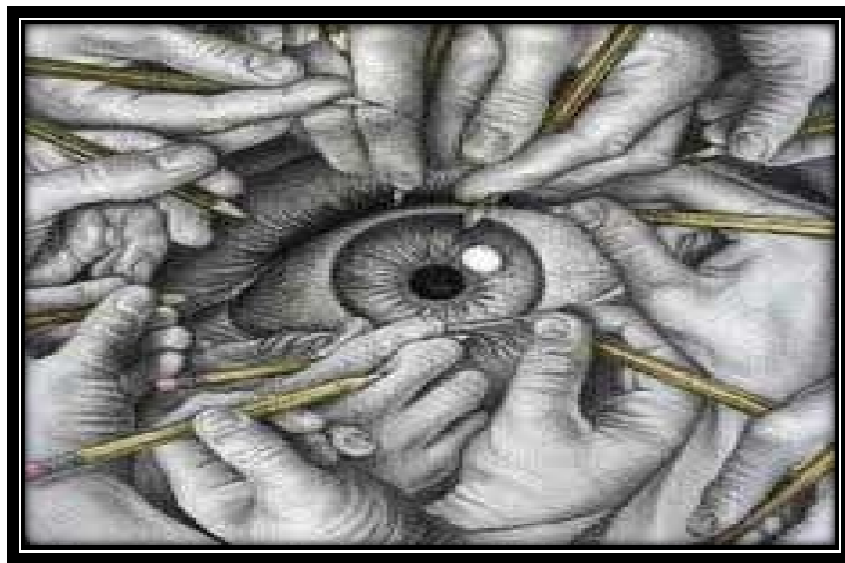
#### **Not broken**

Sandra: *So, one of the huge impacts was actually if I am saying I am ok and there's actually not that much around me that's wrong and needs fixing and other people on the course are saying that as well then maybe that's actually true. I came away with this sort of actually I can just be me there's nothing wrong with being me. Not everybody is going to get me. That's fine! There are plenty of people who do get me. That's a huge, huge relief actually. I am not broken; I don't need fixing; it's ok to be me. That was huge, absolutely huge.*

The MPHl course facilitated explorations of madness and identity in relation to the dominant biomedical discourse on illness and needing fixed. Liegghio (2013) suggests Epistemic Violence is experienced within psychiatry in the medicalisation of distress. For Sandra, the course had facilitated a rejection of this broken identity through the affirmation of peers. Liegghio (2103) suggests that “psy violence” impacts negatively on personhood. The second subtheme related to the course facilitating an analysis and reclamation of identity.

### **Reclaiming lost Identities**

The students talked of the impacts of both psychiatric and societal labels of abuse being imposed on you by others. Eleanor described and visually represented through her Photovoice image from the course, her experiences of losing your identity when you have mental health issues:



Photograph 4: Drawn by others: Losing Self



Eleanor: *My one was an Escher drawing. An eyeball with lots of hands and pencils drawing around it and the eyeball was disappearing under all these hands. That's what it feels like to have mental health that everyone else fucking draws and decides who you are and you get completely lost underneath everything.*

Eleanor revisited her Photovoice image and her interpretation of the image relates to her loss of control within the “psy complex”. Burstow (2013) suggests that “psychiatry is a regime that names the world” (p.80) and “rules by words” (p.89). She advocates for refusal terms such as survivor, inmate and patient as a resistance to the hegemony of psychiatry. Lorraine used the Photovoice image from the course to analyse the impact of stigma and internalising negative labels.



Photograph 5: How one's own sense of identity can be eroded and even changed by others conception of what they think your identity is: Me Mad?

Lorraine: *The image is m. A picture of me stuck in a net. There's words around me. The positive words are sort of stuck in the net with me and get smaller and smaller as people aren't so nice to me. The nasty words are on the outside of the net and those words are words that people have described me as: psycho or mad or schizo. To me it's a lot about my identity and how other people have managed to create my identity for me. I've kind of realised that I need to be more forceful in creating my own identity.*

Labelling theory (Mead 1934) defines labels as socially constructed, problematic and open to interpretation. Negative labels result in stigma, defined as the social attributes of a group being subject to disapproval and being discredited (Goffman 1963). Lorraine describes the impact of the labels others have given her as terms of abuse about her identity. The course facilitated an analysis of this process and a realisation of the importance of the right to self-identity. The third subtheme suggests the course had facilitated the creation of more positive self-identities.

### **Creating New Identities**

The impact of the course revealed a diversity of positive experiences on identity that included: more clarity and confidence, feeling whole and affirmed, feeling more myself and happier.

*Martin: Knowledge gained on the spectrum of experience valued other identities and experience. I can now describe my identity. I didn't know what my identity was. I have an idea of my identity. I didn't know what it was.*

*Shona: I see myself differently. I see myself as a person - a whole person. Before I felt like I wasn't important.*

*Julie: I am much more confident now. I am on the road to recovery. Another six months and I will be myself. I am more myself every day.*

*Patricia: It's about saying: "It's ok to me". It's ok to accept that I have these issues. I have these difficulties and accept me for who I am.*

*Cleo: Self-actualisation is important. I know who I am and I am happy with who I am.*

The students' perspectives indicate that what the students felt on a personal level was influenced by the collective experience of the course. There had been an impact on identity that was informed, affirmed and assertive. This confirms the experiences of the students on the course and the opinion of peers had a positive impact on identity. The literature debates mad as an identity but Eleanor reports that the course had facilitated her self-identification as a mad person and mad activist.



*Eleanor: It's changed me as a person. I've met a lot of new people. I've become a lot more informed. I've wanted to be an activist more. I've felt like I am actually doing something rather than sitting in the pub talking about how shit everything is. I have found a new identity as a proud mad person and an activist so a new label that is positive a mad activist.*

Reclaiming mad as a collective activist stance is asserted by Church (2013a) who states that “the term “mad” is an activist interruption in the discourse of “mental illness (p.1).

Whilst there is a debate about the reappropriation of mad-identity within the literature (Beresford et al 2010, Burstow 2013, Plumb 2015, Russno 2016), Burstow (2013) asserts that there are positives in mad language as it “facilitates celebration and pride” (p.85). Fabris (2013) asserts: “mad is a historical rather than a descriptive or essential category, proposed for political action and discussion” (p.139). Russo (2016) asserts that the experiences of being labelled feared and othered are more connecting than madness and asserts that madness cannot serve as a personal or collective identity but emphasises that “the experience of madness is always a highly personal matter” (2016, p. 65).

Martin's experiences on the course had been twofold in relation to identity. Firstly in exploring the labels he had been given as diagnosis within psychiatry.

*Martin: I have had many labels since I was 17. I have had a shift of identity. I don't see myself as diseased and broken and embracing my identity as neurodiverse. My identity has had a radical shift. Previously I had an idea about identity - occasionally depressed, chemical imbalance. I now consider myself autistic and a neurocosmopolitan citizen.*

Martin describes an activist journey in self-identification and challenge that involved rejecting psychiatric labels and redetermining his own identities as involving neuro diversity and citizenship. The Neurodiversity movement is a more encompassing term that includes people with the experience of attention deficit hyperactivity disorder and autistic spectrum disorders. Graby (2015) asserts that neurodiversity offers a bridge to unite the Disabled

Peoples' movement and the user/survivor movement as this community have roots in both movements.

Secondly the intersectional analysis on the course had started a process of questioning the binary of both his gender and sexuality.

*Martin: My gender-identity has changed. I couldn't explore it and I mourn my beautiful years. I am now exploring both my gender identity and sexuality.*

The PAR group analysis suggested that challenging privilege and was a theme from Martin. When discussing the themes with him, he asserted that whilst acknowledging his racial and class privilege it had also impacted on his ability to self-identify. The course had facilitated analysis of identities for Martin but also a change in how he identified himself in relation to madness and gender. The literature suggests that: "The intersections between neurodiversity and trans and queer identities are already being realised around the term 'neuroqueer'" (Mc Wade et al 2015, p.307).

#### **5.4 Chapter Summary and Discussion**

This chapter has explored the first overarching theme of the experiences and the impacts of the MPHl course on mad-identity. Identity is defined by Fadjukoff (2007) as a psychosocial construct of the way one defines him or herself. Bilton et al (2002) stress the importance of the views, opinions and reactions of others in influencing our self-conception. Reclaiming mad is part of identity politics which is a political agenda based on shared experiences and actions against oppression. Hanisch (1969) is attributed with developing Mills (1970) ideas about personal experiences becoming public concerns by coining the phrase "the personal is political." Reclaiming mad is both a personal and political position.

Mad- identity was a debated concept with many of the students rejecting the reappropriation of mad as part of their identity due to the stigma associated with the term. The history of mad as a term of abuse made it difficult to reappropriate as a positive personal identity. Research by Beresford et al

(2010) revealed a rejection of mad by participants due to it being, negative, labelling and stigmatising. The students also expressed ambivalent feelings about mad-identity that echo the literature and stress the importance of how, where, why and with whom it is used.

The students also viewed mad as positive, empowering and liberating and that mad as a positive identity was a rejection of the medical model. Beresford et al (2010) participants disagreed and did not view mad as offering an alternative understanding, but another negative way of expressing medicalised individual thinking. Burstow (2013) asserts that language is important and both reclaimed and refusal terms challenge the hegemony of the psychiatric discourse and its terminology. Russo (2016) recognises that those who are labelled mad are profoundly connected to the dominant medical explanations of their experiences whether they accept or reject them. Some of the students identified as having mental health problems or illness that provide biomedical explanations of their experiences. Diagnostic labels however are also necessary to get support from services and connect to wider support networks so self determination of them is debateable. The history of belonging to other social movements that have reappropriated language was influential in reclaiming mad. Russo (2016) asserts the importance of understanding and reclaiming madness by finding the right words whilst also asserting that it is a fragile identity.

There are debates within the literature about the use of mad language but scholars are advocating the importance of its use in relation to a critical and political position (Fabris 2013) and its relationship to activism (Church 2013a). The reappropriation of the term mad is predominantly viewed as a conscious political action by activists and scholars. The context was significant and students were more comfortable using mad within the mad community. The need to collectively challenge sanism was highlighted by students as a more important political act than reclaiming mad. Poole and Ward (2013) assert that sanism is a devastating form of oppression that asserts a binary separation of those deemed to be normal, healthy and

capable and those who are sick, incapable and disabled within society. Sanism results in stigma, discrimination and oppression of mad-identified people. The students challenged the binarism of a world where there are the sane, the insane and the mad. The students' responses about an individual mad-identity reflect the debates within the literature. For some it was empowering activism for others associated with stigma and the "psy complex". Mad as an identity was complex, diverse and personal.

We wanted to explore mad-identity within the research. The findings indicate that the course had also facilitated an intersectional analysis of madness, gender, race and sexuality. Patricia explored the impact of gendered social norms on women and how the historical experiences of abuse and medicalisation of trauma had resulted in a gendered BDP diagnosis. Mad scholars have critiqued the relationship and history between madness, child sexual abuse, trauma, and gender (Diamond 2014: Wolframe 2013: Filson 2016: Rubinsztajn 2016). One of the traumas being challenged within the "psy complex" is the reduction of traumatic childhoods and mental distress of women being reduced to a deficit in personality namely the gendered diagnosis of BPD (BDPINTHEBIN 2016).

Cleo explored the challenges of the intersectionality of a mad-identity and cultural identity in the transition of being a black immigrant mad woman. Cleo did not highlight racism in the research within the course but expressed that the course had had an impact on her response to racism. She did however use Photovoice within the course to represent her analysis of her intersectional identity and transition to a different culture. This led to a deeper discussion on madness and race, culture, transition, racism and the fears of her community in relation to madness and psychiatry. There was literature on white privilege on the course but possibly a dominantly white course within a University of white privilege did not make enough space for deeper discussions? The literature is permeated with intersectionality debates regarding madness and race, asserting that Mad Studies is at risk of being an ethnocentric discipline and discourse (Gorman 2013: Tam 2013: King

2016: Gorman and LeFrançois 2018). LeFrançois (2016) asserts that Mad Studies needs to confront racism within the mad movement and acknowledge the privileging of white survivor contributions. Gorman and LeFrançois (2018) assert the need for Mad Studies to promote the racialised and colonised black experiences and histories within the psychiatric system.

Martin had explored the gendered social norms impacting on men in relation to madness, gender and sexuality. Photovoice used on the course had facilitated an analysis of heteronormativity and gender binarism. The importance of an intersectional analysis of multiple identities in order to politically and collectively subvert heteronormativity is promoted by LeFrançois (2013). Intersectional scholars Spandler and Barker (2016) explore the common ground between Mad and Queer Studies and conclude that they both challenge existing binarism, critique normativities. They both need to examine their own histories of inclusion and exclusion.

Russo (2016) asserts that a new paradigm on madness cannot be identity-based. She highlights the critique of single-issue struggles by Mad Studies scholars (Diamond 2013;Gorman 2013) asserting there have been failings in the Feminist movement and the Gay Liberation movement in their exclusion of mad women and trans people. The literature advocates acknowledging the intersectionality of mad-identity with the identities of other oppressed groups. Pilling, researching the intersectionality of madness and LGBT identities (2013), asserts that intersectionality is used to theorise how race, class, gender, sexuality, and disability operate together to shape identity, experience and the impact of power relations on both individual and institutional levels (p.1).

The findings suggest that the course had a positive impact on how the students felt about their mad identities. Self-identity had been enhanced. They reported being able to challenge the negative psychiatric and societal labels they had received from others. The MPHI course had facilitated explorations of madness and identity in relation to the dominant biomedical discourse on illness and needing fixed. Burstow (2013) suggests that

“psychiatry is a regime that names the world” (p.80) and “rules by words” (p.89) and these words need to be both refused and reclaimed. Students reported that they were reclaiming lost identities and had embraced new identities beyond medical diagnosis of ‘activist’ and ‘neurocosmopolitan citizen’. Positive self-determined identities were important impacts of the course. This is reinforced by black feminist thinker Hill Collins (2003) asserts that self determination is the first step to empowerment.

The students reported that the experiences of mental distress and psychiatrisation are inextricably linked to identity under this first overarching theme. However, the impact of mental distress and psychiatrisation went beyond identity. This is explored in more depth in the second overarching theme in Chapter Six: Madness, Mental Distress and Psychiatrisation.

## 6. Chapter Six: Madness, Mental Distress and Psychiatricisation

This second of the four overarching themes focuses on the students' own experiences of madness, mental distress and psychiatricisation. Throughout the analysis of the data there was a dominance of perspectives about lived experiences. Students reported that exploring their own experiences and history had been an important experience on the course. The two sub themes generated are the embodied experiences of mental distress and experiencing psychiatricisation. The themes and subthemes identified under each theme are represented in Figure 3.

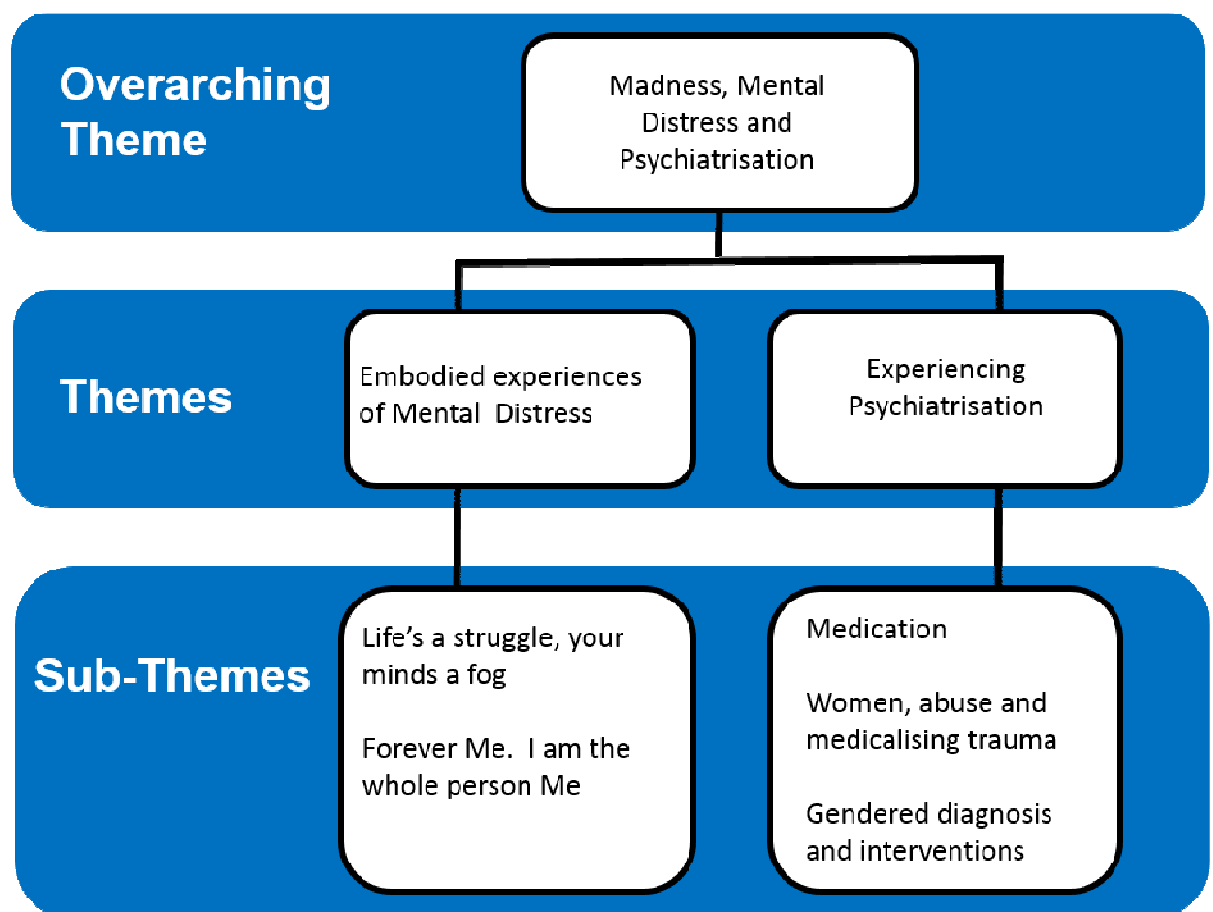


Figure.4: Second overarching theme: Madness, Mental Distress and Psychiatricisation: themes and subthemes.

Mad Studies is a movement that celebrates mad experiences without pathologizing, glamorising or effacing an experience that may be deeply distressing (Gorman and LeFrançois 2018). The students asserted that revisiting their personal and collective mad experiences on the course had been useful but also traumatic. Patricia shares the impacts of the course:

*Patricia: It made some connection. Actually, it wasn't easy in terms of some of the ways in which I have been having to reflect about things. It's been quite a struggle and certain things like this is the path I've come through it. I am off my medication I've got on with my life every things ok. Some of these connections and needing, having to speak out to explore it a bit more and I have been retraumatized a bit by the course. But then it's also leading me on to other things and speaking out more. So, it's a double-edged sword. These connections I need to explore to come to my identity. It is not easy. It's been a trigger for stuff that has been happening for instance managing day to day with work stuff. I was finding myself dissociating. I was a bit naive. I have always coped. I felt I have already done this. I will be fine. I didn't feel it was going to open up anything to me. I didn't anticipate the personal impact it would have on me.*

Patricia's experience is important in reinforcing the need for support and debriefing sessions in a course that explores individual experiences and histories as a starting point to collective analysis.

### **6.1 Embodied Experiences of Mental Distress**

The first theme that was generated was the embodied experiences of mental distress. Julie discussed her experiences of PTSD. She used her Photovoice image from the course to illustrate her experience.





Photograph 6: Life's a struggle, your minds a fog

*Julie: I was diagnosed with PTSD two years ago and anxiety and depression. While I was somewhat relieved I was given a diagnosis, it did make me wonder if getting a diagnosis would make me madder. It was a guy on a push bike. I chose that because it meant wheels is a cog - a road just spinning round the human race. Life's a struggle you are constantly pushing forward sometime you get somewhere and sometimes you don't. You push on regardless. That's to me mental illness. You try to recover then you relapse. It's up and downs. You get your up days and your down days. It's hard to concentrate with all this confusion in your head with PTSD. It's like what I was saying about the PTSD. Your brain is trying to get out of the fog. You sit and stare into space. You get overwhelmed by thoughts and people. You are not living. It's like seeing your vision. It's like looking through glasses you can't see properly. Your mind is a fog.*

Shona added to this theme sharing her experiences of mental distress.



Photograph 7: Forever Me. I am the whole person: Me

Shona described her experiences as suffering from mental health issues. She shared her experiences and the impacts of depression anxiety and phobias.

Shona: I chose the image because it was like a there was all different avenues of myself and you had the dark side and the normal side as you would put it. There were different messages coming in from different areas in my aura so I described them and how that's how I felt people can look at me and think there isn't any problem with my mental health. It shows the positive and negative side and the dark and the light. It was important. I am a 57-year-old woman. From the day I came into this world, I believe my path was to suffer from mental health issues. Not by choice but who I am. I haven't known what it is like to be without depression, anxiety and phobias. It's "Me" part of "Me". I live with that. I've been in dark places in my mind but also wonderful places. I am part of "Mad People's History".

Julie and Shona talked of the struggle of mental distress and how mental health issues had become part of their lives and identity. O' Hagan (2016) asserts that mental distress must be viewed from the perspectives of those who experienced it and viewed as an experience that whilst challenging has value and meaning. The value and meaning of lived experience is conceptualised as experiential knowledge. MPHl aims to create a space where the students can discuss individual experiences of madness. They inevitably involved experiences within the "psy complex". The second theme generated was the impact of psychiatrisation.

## **6.2 Experiencing Psychiatry**

The experience of psychiatrisation was a dominant theme throughout the analysis. It involved diverse impacts that were predominantly gendered and the voices of mad women. The experiences were generally negative and the medicalisation of distress and the harm done by psychiatrisation. Liegghio (2016) defines psychiatrisation as follows: "Psychiatrisation refers to the processes and mechanisms through which certain persons, adult or child, come into psychiatry as a political realm" (p.110). Beresford (2013, p.ix) states that despite its dominance, many mental health service users report that its medical model is not only unhelpful but indeed damaging.

The students shared their experiences of the harmful effects of psychiatrisation. Illich defines this harm as iatrogenesis:

.....The medical establishment has become a major threat to health. The disabling impact of professional control over medicine has reached the proportions of an epidemic, iatrogenesis, the name for this new epidemic, comes from iatros, the Greek word for physician and genesis meaning origin. (Illich 1978, p.11)

The subthemes generated were: medication, women, abuse, medicalising trauma and gendered diagnosis and interventions.

## Medication

Medication was the first subtheme. Patricia and Cleo reported the harm caused by dependency and the side effects of medication.



Photograph 8: Medication, Dependency and Iatrogenesis

*Patricia: One of the biggest things was the medication and that was what I had relied on most for twenty years. I believed that if I stopped taking my medication I would die. I needed it. I had been told this when I was 15 years old: "You need this medication. You are going to have to take it for the rest of your life. If you don't take it, you will become very ill. You probably won't survive. You will probably live in hospital for most of your life". There were those messages I had.*

The side effects of suicidal ideation of antidepressants were shared by Cleo:

*Cleo: I think the medication caused my husband's suicide. It was a side effect. It could have been avoided if he had been seen on time or told to watch him one on one.*

Patricia shared her complex experience of taking medication. This included it being helpful but also causing harm through withdrawal.

*Patricia: Once you are on the medication, even though you might experience it as something negative in that you feel like really sedated, you have problems with side effects some of which can be really unpleasant. At the same time, it's numbing down all the distress in your head. The fact that you don't have this enormous distress it's not how*

*you get on and how live your life. Suddenly the medication is taken away and not only have you had twenty years where the thing in your head is controlled by this chemical and suddenly it's not. You have to learn to deal with it in a different way but you haven't been given any skills to do that because you've been given this chemical straight jacket. On top of that the impact of chemical been taken away your mind goes a bit mad. Your normal level of psychosis mad thinking goes through the roof and you think the doctors were right. I need to take the fucking medication.*

The issue of medication was discussed openly on the course. Patricia shares her experience of taking medication but stresses the importance of choice. She also highlights the diversity of the positions of the students in the research regarding medication and psychiatrisation.

*Patricia: I was aware that I was quite outspoken about my experiences and felt that psychiatry harms people and I was aware that some people were still using services and were still dependent. Everybody has the right to make the choice about medication. I need to take medication to get through the day but it has to be an informed choice. People will make different choices. There was some tension in terms that there is so much evidence about the harm of medication, efficacy of psychiatric medication. Sometimes it was uncomfortable. This is my experience and I need validation.*

Cleo highlights a positive view on medication but highlights the risk of harm to her unborn child:

*Cleo: I have been prescribed anti-depressants myself. I was quite keen on them and I saw the counsellor who spoke to me and that was all I needed. The counsellor asked if I was pregnant. I did pregnancy test and was positive. I am glad my baby wasn't exposed to medication*

The impact of medication was a complex issue and students described it as helpful and harmful. The medical model is also critiqued within the literature as having an over-reliance on medication. There is a vested interest in promoting pharmaceuticals due to the co-dependent relationship with pharmaceutical companies that dominate health care agenda as described as "Big Pharma" (Law 2006). The second subtheme to be generated was the experience of abuse and the medicalisation of trauma within psychiatry.

## Women, Abuse and Medicalising Trauma

The female students had touched on the gendered experiences of identity in relation to diagnosis and the social norms imposed on women. They had described the misdiagnosis of trauma. This will be more fully explored in this part of the thesis. Students revealed both a historical and current analysis of this experience. Margaret produced an image that represents the historical abuse of women by men who had the power to have them incarcerated in asylums.



Photograph 9: Patriarchy, abuse and confinement

*Margaret: I was very interested in the past I liked history. I picked Victorian women in asylums looking sad. You were married, your husband could decide what to do with you. Some places were open not that long ago. There was nothing wrong with them. I didn't have a bad experience but I was only in hospital briefly. I heard other people's stories. I was taken advantage of at work and that led to me being unwell.*



Margaret expressed that this topic had been motivated by the stories of others but not her own personal experiences of psychiatrisation. Through the thematic analysis, I asked Margaret if picking the images of women had any relevance to her own experience of mental distress as a woman. She replied:

*Margaret: I was exhausted and not sure what to do. I was taken away to hospital twice. I don't remember much about it. I don't tell my story sometimes I tell bits of it to close friends and family. I am more aware of the risks of living on my own as a woman.*

The PAR group had analysed Margaret's comments as being generally about her interest in the experiences of women as a woman herself. In sharing the analysis, it was clear that this had more personal resonance with her feelings of being vulnerable as a woman living on her own and that her memory of being hospitalised was poor. She was reticent about sharing her personal story of distress and psychiatrisation.

Patricia exploring her Photovoice image of women also discussed the historical abuse of women. She asserts that BDP is the new hysteria.

*Patricia: Looking at links of how women have been treated over time. - forbidden women. Looking at women's experiences in the 19th century, the most common diagnosis was hysteria and how women were treated with hysteria, the bizarre treatment and how that could be viewed as sexual abuse. It was about controlling women about who they should be. And if we diverge, it's not acceptable - look pretty not angry. Women used to be called witches and burned at the stake. Women diverged. We were burnt at the stake and then we were put in the asylum and named as being hysterical linked to our sexuality. What's moved on from this is what's taken over as BPD from the hysteria label.*

The scholarly critique of madness and women has expanded to include the experiential critique through the narratives of women who have experienced violence and iatrogenesis through confinement within psychiatry (Diamond 2013, 2014, St-Amand and Le Blanc 2013). Their experiences highlight the historical power of men to commit women and reflect the misogyny and oppression of a male dominated society in which psychiatry was an integral power. The negative attitudes to women and mental distress meant they were diagnosed with labels such as hysteria and experienced abuse within

psychiatry. The personal abusive histories of women were expanded upon by the students under the subtheme of being retraumatised within psychiatry.

### **Retraumatization within Psychiatry**

A dominant theme in the literature is the historical abuse of girls and women within psychiatry. This abuse entails both medicalising the trauma of sexual abuse and the experience of sexual abuse by the professionals within psychiatric institutions.

Patricia's experience of being sexually abused as a child was further traumatised by sexual abuse by a senior male nurse when admitted to adult services:

*Patricia: Right from the day I was admitted there was the experience of one of the senior nursing team ward managers was started to abuse me. I couldn't understand in my mind why he was doing this, if it was part of my treatment what was happening. Absolute terror and not able to speak out, not being able leave this place - it was such a traumatic experience. From what began as an issue of touching, to bullying to raping me, over a period of time. What happened to protect me? I was given a single room to protect me but it made it worse because he was coming in. This was happening in my mind I didn't understand what was happening.*

Mad scholars have critiqued the relationship and history between madness, child sexual abuse, trauma, and gender (Diamond 2014: Wolframe 2013: Filson 2016: Rubinsztajn 2016). Diamond's critical ethnography revealed that the gendered nature of society and its social institutions are reflected within the current "psy complex" practices and in the historical abuse of girls and women within psychiatric institutions.

Female students shared that psychiatry responded to their experiences of abuse by medicalising it and giving them a label of BDP. This gendered label will be explored in the next theme of medicalising trauma.



## Medicalising Trauma

Patricia reported that her childhood sexual abuse and her response to this trauma were medicalised with confinement and medication. The problem was located within her behaviour as opposed to recognising that she was a distressed, traumatised child.

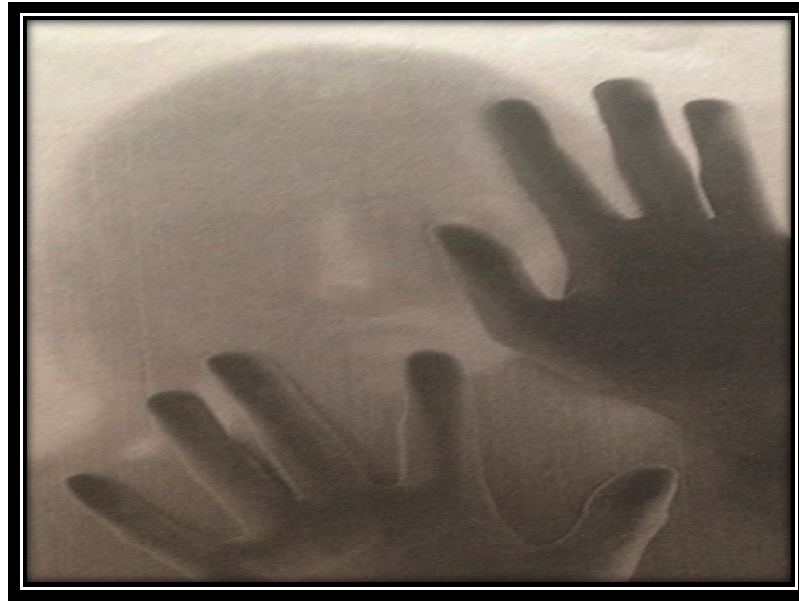
*Patricia: I ended up in the system when I was very young. I was referred for psychiatric help when I was 12. I think it was my way of coping with what was going on terms of the abuse that was happening in my childhood drove me to the attention of the mental health services. I was self-harming. I was first in an inpatient facility at 13/14. I was dumped into an adult ward and not protected at all. It was really horrendous the drugs they gave you. The first psychiatric ward I was admitted in...first the whole process about being admitted.. the questions that were being asked: "Was I sexy or being promiscuous?".. For a young child who was trying to survive abuse and trying to escape things.*

Sandra's experiences echoed Patricia's in reporting the gendered nature of the medicalisation of trauma

*Sandra: Off and on during the course, we talked quite a lot about trauma. As well as myself, there were people on the course who really felt that their mental health diagnosis came from traumatic experiences. It was something that I felt really strongly about because I have been through a hell of a lot of stuff. It really annoys me to this day that women in particular have been through some appalling things are then labelled as being mentally ill.*

Filson (2016) asserts the importance of trauma-informed approaches and relates to her lived experience of trauma with the medicalisation of her distress. She advocates for trauma-informed approaches that understand the links between trauma and mental distress. These approaches are committed to preventing the retraumatisation of people with a history of trauma induced distress. It was clear that trauma had not been identified or appropriate interventions offered for Patricia or Sandra. As previously discussed by Patricia, BDP is considered by the mad movement as a gendered diagnosis that is being challenged by activists. This experience will be explored under the last subtheme of Gendered Diagnosis and Interventions.

## Gendered Diagnosis and Interventions



Photograph 10: Being Borderline? Medicalising trauma and blaming me.

*Sandra: The photograph I have chosen represents the effects that trauma, psychiatric medications and society's reactions to my distress has had on me. It illustrates how I feel like I have been made to live in a bubble.*

In dialogue with Sandra she expanded on the impacts of trauma, BDP diagnosis, medication and the social impacts of madness.

*Sandra: The image is if you imagine somebody standing behind a glass shower screen it's all steamed up from the shower. There's me behind it. I am pushing to try and get through but you can't see me. You can see my hands pushing and you can see a silhouette through the glass. I chose that image because I feel that the medication that I have been made to take for thirty-odd years and the trauma I have gone through for a lifetime and also the way that society views me because of the way I am have made me feel like I am shut off. I am trying to push through but I can't get through. It's too hazy and too solid, so it's that step back. I am not quite with you. That really spoke loudly to a lot of what I have been through. Not many people know a lot about me - that distancing - I am different now again it's that disconnect.*

## BPD and Interventions

Patricia critiques the use of medication for women labelled as BDP

*Patricia: Although the most often and usually first line of treatment prescribed for most people diagnosed with this disorder in the UK is drug therapy, usually antipsychotics and/or mood stabilisers. Despite the fact that NICE, when reviewing treatments available, found no evidence that any medication is effective in treatment, recommending they are only used for short term management of symptoms.*

Patricia is critical of Dialectical Behavioural therapy as a therapy for BDP. She presents this critique through her Photovoice image and narrative of the Stepford Wives.



Photograph 11: Dialectical Behavioural Therapy: Effective Treatment for BPD or a “Stepford Wives Therapy” Programme? (AKA) The Anti-Psychiatry Movement: Irrational Hostility or Common Sense)

In dialogue with Patricia, she asserted that gendered societal expectations of women were linked to dialectical behavioural therapy viewed as a gendered intervention.

*Patricia: It was an image from the Stepford wives - an eerie tale of women being brainwashed into robots. Through work the recent treatment being offered for BPD was dialectical behavioural therapy. I had to look at it reading the handbook. I was shocked. It seemed really like sexist - be mindful, behave nicely, radical acceptance. In issues around trauma and abuse you are not allowed to be angry - women aren't angry. Letting go of your anger radical acceptance - this group of men who abused you have to accept this has happened - can't change reality - accept the pain. Think about your abuser I found really offensive. This is what women like me are being offered. It makes me feel really angry.*

One of the traumas being challenged within the “psy complex” is the traumatic childhoods and mental distress of women being reduced to a deficit in personality namely the gendered diagnosis of “Borderline Personality Disorder” (BPD). There is an activist grass roots movement challenging the validity of this label and campaigning for its resistance, opposition and critique. The guide to avoiding a diagnosis of ‘personality disorder’ number one suggestion is; “Try not to be female (for bpd)” (BDPINTHEBIN 2016).

### **6.3 Chapter Summary and Discussion**

The experiences of madness, mental distress and psychiatrisation permeate the findings. They were revealed in dialogue throughout the data and subsequently identified as an overarching theme. There was however a distinction between students who described their experiences of mental distress and those who were critical of the distress and harm they had experienced through psychiatrisation. The subthemes generated were the embodied experiences of mental distress and experiencing psychiatrisation.

The students reported that exploring their own mad history through the discussions in class and the Photovoice project had been an important, if at times traumatic, part of the MPHl course. Patricia highlights an important finding that the process of consciousness raising through sharing of

individual and collective lived experiences of mental distress can be retraumatising.

The embodied experience of distress was shared as the struggle of mental distress that had become part of your life. The social model of disability has been critiqued for its lack of focus on the embodied experience of impairment (2013). This debate has also appeared in the Mad Studies literature.

Mental distress needs to be viewed primarily through the eyes of the people who experience it. It is a legitimate and challenging experience from which value and meaning can be derived (O'Hagan 2016).

The second subtheme generated was experiencing psychiatrisation. The students who created the data on this topic were all women. The dominance of the biomedical model in understanding distress and responding to that distress was evident. This reflects the Mad Studies literature as captured by Poole and Grant:

.....The medical model of mental illness/health is based on a system that often locates the "problem" within an individual, takes that individual out of their context and community, and seeks to treat and change. In the name of "best practice," those treatments may be iatrogenic, involve multiple rights violations, as well as perpetuation of a kind of discrimination known as sanism. (Poole and Grant 2018, p.305)

Medication was the first subtheme of experiencing psychiatrisation. The students were positive and negative about its use. They reported using medication but also harm through dependency and side effects and a lack of choice in its use.

The experience of mad women in a patriarchal psychiatric system and society was a dominant theme woven throughout the findings. This became the second subtheme from the data analysis of women abuse and medicalising trauma.

The experiences of women in relation to confinement and "psy violence" have been critiqued within the Mad Studies literature (St-Amand and LeBlanc

2013, Diamond 2014).The historical literature is permeated with their narratives of trauma abuse and the medicalisation of distress.

The retraumatisation of psychiatrisation was identified as a theme. Patricia shared her experiences of being sexually abused as a child, being admitted to an adult psychiatric ward as a result of her distressed behaviour and then being repeatedly sexually abused by a Senior Nurse.

Mad Scholars have critiqued the relationship and history between madness child sexual abuse, trauma, and gender (Diamond 2014: Filson 2016 Wolframe 2013: Rubinsztajn 2016). Diamond's (2012) critical ethnography revealed that the gendered nature of society and its social institutions are reflected within the current "psy complex" practices and in the historical abuse of girls and women within psychiatric institutions. Diamond cites one of her participants asserts that psychiatry is where women end up who have experienced violence. Connell (2009) asserts that reported incidence of domestic violence, rape and child sexual abuse represents a marker of male power and female vulnerability.

The current Scottish government enquiry into childhood sexual abuse is focused on residential homes and remand centres. The extent of the sexual abuse of children and women within psychiatric institutions is yet to be fully investigated by the UK and Scottish Governments.

The last theme generated was Gendered diagnosis and interventions. Receiving a diagnosis can have positive or damaging impacts as described by Rose:

.....Mental health problems occur in a world of meaning and psychiatric interventions can themselves alter that world. Receiving a diagnosis can be a relief but also can have profoundly damaging effects on a person giving rise to a "master status" whereby the whole person is reduced to only their diagnosis (Rose 2008a, p.448).

The gendered experience of a BDP diagnosis was described by the students as having your trauma medicalised and resulting in stigma and isolation. Patricia and Sandra reject this diagnosis as do many other women.

Rubinsztajn (2016) supports the students' experiences that women's trauma is labelled as difficult and personality disordered resulting in their experiences pathologised and overwritten. The impact of the isolation of BPD diagnosis is supported by Sagan's (2017) research that evidenced the links between BPD diagnosis, loneliness and trauma. The students assert that there are no positive interventions from the "psy complex". The importance of trauma – informed approaches are asserted by Filson (2016) related her experience of trauma and the medicalisation of her distress.

The findings indicate that course facilitated an exploration of the students' experiences of mental distress and psychiatrisation. It also raised individual and collective consciousness about the gendered abuse and violence within society. The findings are consistent with the literature regarding the abuse, trauma and medicalisation of trauma women have experienced within the "psy complex". It indicates a wider problem of sanism and sexism within society that results in referral to psychiatry and being psychiatrised. The voices of the women within this research reveal the dominance of a biomedical response to their distress and the diagnosis of BPD resulted in stigma and isolation. Photovoice images created on the course were dominantly focussed on the lived experience. Six of the students revealed a female perspective by using this method on the course to explore their experiences of madness, mental distress and psychiatrisation.

The students within the research with a BDP diagnosis are currently part of the BDPINTHEBIN movement which challenges BDP as a diagnosis. This leads us to the third overarching theme which was that the impact of the course was generating knowledge, facilitation agency and activism.

## 7. Chapter Seven: Knowledge, Agency and Activism

The third overarching theme generated from the data was the experiences and impacts of MPHl on developing knowledge, challenging dominant knowledge, conscientisation, agency and becoming involved in activism. The themes and subthemes are presented below in Figure Five:

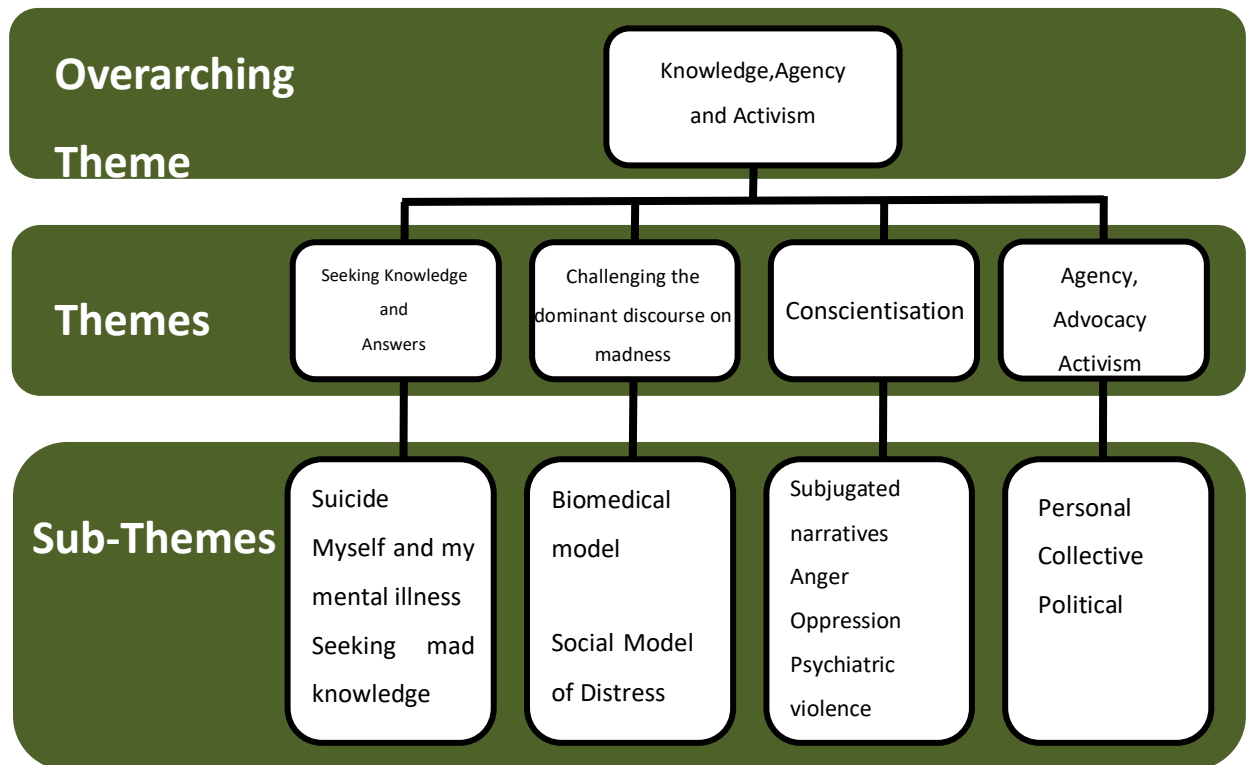


Figure 5: Third overarching theme, Knowledge, Agency and Activism

### 7.1 Seeking Knowledge and Answers

The first theme generated reflected that the students were motivated to attend the course by seeking answers to their own experiences of mental distress and that of family members, but also to gain useful knowledge about mental health and madness. The first subtheme was seeking understanding of suicide.



## **Suicide**

*Cleo: I have always been interested in mental health - not always but generally in life. When I came abroad, an incident happened with my husband where he died by suicide. I had not really witnessed mental health. It prompted me to look for answers to my questions.*

*Shona: Well I've always suffered mental health problems from a very young age and when I heard about the course and I was going through tragedy at the time, I was grieving for someone that died with mental health problems.*

Grief was an experience that had motivated people to come on the course. Poole and Ward (2013) discuss "Mad grief" asserting the importance of sharing stories of loss that are frequently subjugated and pathologised. The course and this research have facilitated a space to share mad grief. This was also a space to discuss and understand mental distress. The second subtheme was seeking knowledge about mental illness and experiences of distress.

## **Myself and My Mental Illness**

*Julie: I wanted to learn more about myself and my mental illness. I wanted to make sense of my PTSD. This was one of the steps to recovery.*

*The third subtheme generated was on seeking mad knowledge.*

## **Seeking Mad Knowledge**

*Shona: I would go on the course tomorrow. It's opened my mind up and I want to learn more about mental health and disabilities and have the knowledge*

*Cleo: I can go back home. I can inform better practice back home. How do Mad Studies inform better practice in Africa?*

The students revealed that they saw the course as an opportunity to gain knowledge. Their expectations were diverse. The focus on their lived experiences is supported by McLaren (2017) who asserts that "knowledge should be examined not only for the ways in which it might misrepresent or

mediate social reality, but also for the ways it actually reflects the daily struggles of people's lives (p.69).

A core premise of critical pedagogy is that truth is socially constructed and that it is dependent on context, history and power (Foucault 1972). It is relational and not absolute (Arent 1958). There was, however, a prominent theme within the findings that the knowledge generated had facilitated challenging the dominant discourse on madness. This became the second theme.

## **7.2 Challenging the Dominant Discourse on Madness**

The first subtheme was the students challenging the dominant biomedical model. The students responded to how the knowledge gained in the course had impacted on their responses to the biomedical model.

### **Challenging the Biomedical Model**

Patricia shares that she was already on a journey of rejecting the biomedical model prior to the course:

*Patricia: I was using mental health services over quite a long period of time - probably 20 plus years. During some of that time, I was an inpatient or in constant contact with mental health professionals. I think I had made a jump from that quite a long time ago in that I had got to the stage when I identified this was doing me more harm than good. I had made a decision to jump ship as it were and to distance myself from mental health services and just actually stop using them. In my mind I had already separated the whole mental health system and psychiatry. How it works was doing me harm.*

Sandra attributes her rejection of diagnosis as a helpful construct to her experiences on the course.

*Sandra: At the time I was working as a peer support worker with people with a dual diagnosis - mental health and addiction. The course impacted hugely on the way I worked with those people. I had been guilty of seeing those people as a diagnosis because when I got these people to work with, I was told this was their diagnosis. I was internalising what I had been told about people. After doing the course I went to my supervisor and told her that any new people I am working*

*with I don't want to know their diagnosis. That was big as well - the way I worked with people.*

Cleo critiques the cultural exclusion of the biomedical model:

*Cleo: I saw that Africans are being treated by the medical model and that's why a lot of people are not coming forward. The Church is the remedy. I am interested in cultural perspectives of mental health.*

In addition to rejection the biomedical model the students challenged the power of psychiatry:

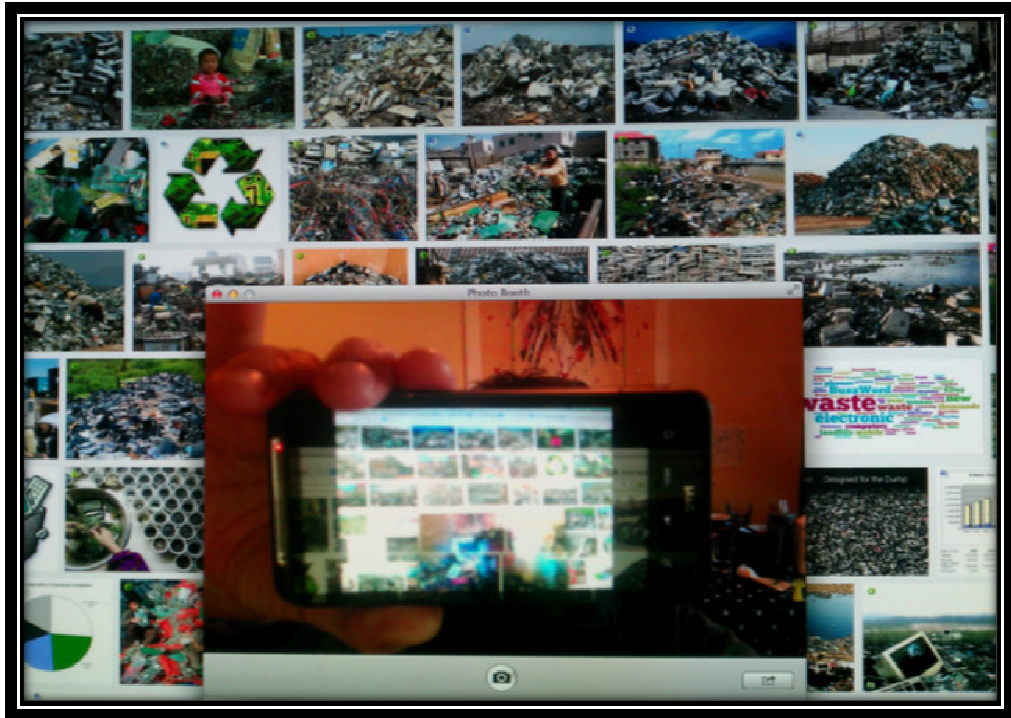
*Patricia: How can we change the system to stop people being abused or damaged in the first place, instead of covering it up and blaming the individual? This psychiatric hegemony is controlling everything and we need to challenge that.*

Martin critiqued that it devalues the experiential knowledge of mad-identified people.

*Martin: My way of thinking is not valued by reductionism. Mad is looked down on by patriarchy that doesn't value other ways of thinking.*

The students were critical of the dominant biomedical discourse and its practices which they describe it as harmful and ethnocentric. The practices include: unhelpful diagnosis, abuse of power and the devaluation of experiential knowledge. The literature suggests that Mad Studies should focus on a critique of the dominant biomedical discourse and its practices. Sweeney's (2016) critique includes the dominant biomedical discourse and the dominant hegemony of the "psy complex". She promotes the importance of creating alternatives to psychiatry's dominance centred on the inclusion of survivor knowledge and the experiences. Mad Studies is grounded in the knowledge of those with the lived experience of psychiatrisation and takes a "subversive standpoint relative to the governing paradigm of psychiatric 'science'" (Menzies et al 2013, p. 11). One alternative model within the literature is the adoption of a social model of distress (Beresford et al 2010). Martin had selected this image whilst on the course to suggest alternative social approaches to madness.

## Social Model of Distress



Photograph 12: Is Society Mad?

The critique of the dominant biomedical model was also related to the exploration on the course of a social model of distress. The students shared that the course had facilitated a social critique of their personal experiences of distress and psychiatrisation.

*Martin: Here I am using my own electronics. I am reflecting on images of society's vast and poisonous electronic waste. Like society I am on my own cathartic journey, which will raise my awareness of my condition, challenge my identity and my acceptance of my diagnosis and then with luck will enable me to generate coping strategies. Courses about mental health facilitate this journey and allow the participant to re-evaluate their identity with regard to their own mental health.*

Patricia supports the premise of the social model of distress that locates the social context as causing mental distress and advocates for social responses to that distress:

*Patricia: It looks purely at the individual. It doesn't look at the social context of that person. It doesn't look environmental factors, and it doesn't look at how maybe cultures have influenced your behaviour. It*

*doesn't look at the role of abuse and deprivation and everything or how you have been impacted by depression. It seems very much around a system which if you were in distress it just looks purely at you and gives an explanation which is around a sort of medical model that there is something wrong with you. It doesn't look at maybe what has happened to you that might have caused you to be in this distress. It doesn't look at the wider question of why this has happened to you. Perhaps if you are part of a group which is discriminated against perhaps if there are wider societal issues which mean that people experience injustices within society which causes people to be distressed.*

Eleanor adds to the social critique of the dominant discourse:

*Eleanor: the history of mad people makes you understand why we are here and why it's still a bit slow - the medical model and social mode. I learned a bit about that, that's a huge thing for lots of people cause it completely changes your whole mindset cause if you don't know about these two models the one that we are given is that we are broken and it's our fault and we should fix ourselves rather than we are sensitive people that have had fucking certain experiences and this is how your body and brain reacts to shit things which is completely different. That's huge - not only do you have to deal with all the shit and mental health that you have but you blame yourself for it all. The social and medical model was important.*

The course had facilitated a critique of the dominant biomedical discourse of the “psy complex” and generated an analysis of their personal experiences through a social lens. The literature suggests a need to seek social alternatives to understandings of mental illness. Beresford et al (2010) explored service users’ responses to a social model of distress influenced by the social model of disability. They conclude:

*.....As we have seen, while disabled people frequently find the social model of disability helpful and identify with it, mental health service users seem much less likely to feel it can be helpful for them and are also often reluctant to identify as disabled. (Beresford 2010, p.31)*

There is a diversity of user/survivor-led alternatives to the “psy complex” within the literature. They include trauma-informed approaches (Filson 2016), peer support (Filson and Mead, 2016) survivor-led services (Staddon 2016, Rubinsztajn 2016, Bhakta 2016, Simpson 2016).

### 7.3 Conscientisation

The Freirean concept of conscientisation, involves the development of critical consciousness through a process of reflection, action and dialogue about the individual and collective experiences of oppression (Freire 1970). The students reported that the course had raised their consciousness about a diversity of topics, experiences and emotions. This included: the historical excluded and subjugated narratives, individual and collective anger and the oppression and violence experienced by the students. This became the first a subtheme.

#### Subjugated Narratives

There was a consciousness described about the exclusion of experiential knowledge and narratives.

*Patricia: I had been quite interested and read quite a bit on the history of psychiatry but again I realised actually that was about the history of what was done to us rather than our experience as of people who had been through the system. I felt it was a really important thing actually in terms of to look at things from the point of view of our experiences.*

The literature suggests that revealing subjugated knowledges resonate with the mad movement's aims and activist endeavours. These endeavours aim to make visible the forbidden and excluded knowledges about the experiences of madness, psychiatrisation and oppression. Menzies et al (2013) assert that "the practitioners of Mad Studies are concerned with deploying counter-knowledge and subjugated knowledge as a strategy for contesting regimes of truth" (p.14). In addition, Mad Studies has an aim to increase the credibility of mad knowledge by addressing the Epistemic Injustice experienced by the mad community. A second subtheme was the importance of collective anger.

## Anger

This included anger about individual and collective experiences. Conscientisation frequently starts with anger at one's own oppression and the oppression of others.

*Martin: Angry at own and others experiences of the system and the lottery of it. It felt I was lucky that the diagnosis that had been given to many of us. I got off quite lightly that I wasn't on large amounts of pills and pills and pills all the problems. I was just so angry because of the deconstruction of the medical model of mental health. Angry for the luck that's involved in the journey of one's catharsis due to the individual nature of the psychiatrist and the category basis of DSM.*

## Oppression

There was also a collective consciousness about oppression and violence.

*Eleanor: The stuff about how mad people have been treated - we have been marginalised, oppressed, tortured and used as guinea pigs, a lot of it because science didn't know any better.*

## Psychiatric Violence

In addition to oppression there was a consciousness about the experiences of "psy violence".

*Julie: I was shocked to learn how people were treated in asylums and society in the past and still are in the present.*

*Martin: Humbling hearing from ECT patient with high IQ that the treatments had reduced her IQ and the way she dealt with the anger. She wasn't angry. Felt privileged and humbled and moved to listen to her story.*

The task of critical pedagogy is to bring members of an oppressed group to a critical consciousness of their situation as a beginning point of their liberation. It is defined by a process in which individuals develop a deep awareness of the social structures that oppress them individually and collectively and result in resistance and counter-hegemony (Giroux 1983, p. 111). The course had facilitated conscientisation through the critical analysis of individual

experiences and engaging in Mad Studies literature. There had been a collective conscientisation of madness within the course.

## **7.4 Agency, Advocacy and Activism**

There are numerous definitions of agency and activism from different ontological positions. The central debate within the literature is the relationship between the agency of human beings and the power of societal structures. From a social psychology perspective, Bandura (1997) asserts that human agency is exercised through three different modes: personal, proxy, and collective. Personal agency is an individual process by which an individual changes what is within their control.

### **7.4.1 Personal Agency and Activism**

The students credited the participation in the course as facilitating personal agency. Under this subtheme the students revealed that personal agency was facilitated by growth in self-sufficiency, self-confidence, courage and lack of shame:

*Jane: I am learning to be self-sufficient. I've never done that. It's all been one thing and another thing. It doesn't happen overnight. It helped me to be more self-sufficient. It gives you confidence.*

*Shona: My confidence had got stronger through the course and I had the courage to talk about my positive times and I also had the courage to open up to anyone who was willing to listen about the personal dilemma of things.*

*Julie: You feel like you have got a voice. I am no longer ashamed speaking about my mental illness. If people don't like it then that's their problem. I don't take it personally anymore. It feels good.*

Personal agency is a prerequisite to activism. The second agentic subtheme was empowerment around work and in questioning and challenging psychiatrists.



## Empowerment

Empowerment was a term used throughout the findings to describe the experiences and impacts of the course. McLaren (2017) defines empowerment: "Empowerment means not only helping students to understand and engage in the world around them, but also to exercise the kind of courage needed to change the social order where necessary" (p. 69).

In relation to work Eleanor reported feeling more empowered going to the job centre and in the sort of work she considers:

*Eleanor: Sometimes I feel more powerful but not all the time - going to the job centre rather being mortified and embarrassed and guilty. Realising it's them that are not really equipped and need retrained. Realising what sort of just not any work that someone with mental health needs to be in the right job. Before I would have taken any job and it would usually be detrimental. I am a bit stronger in what I want from life.*

Sandra reported being empowered to leave voluntary work:

*Sandra: I eventually stopped peer support. I started to see things in the peer support work around the recovery model that I wasn't happy with. I was working with people differently. I felt you are taking advantage of me as I did it voluntary. You expect me to bare my soul as a peer support worker. It empowered me to stop doing that. A person shouldn't have to earn their place to bear your soul every time they meet someone.*

Empowerment to question and challenge psychiatrists was shared by Martin and Julie:

*Martin: Most powerful things that happened to me on the course was going through this identity change - being equipped with the self-esteem confidence language and ideas to challenge my psychiatric treatment. I wished to seek an autistic diagnosis. Through this course I began to view my psychiatrist as a peer. By talking to him as a peer I got a referral and diagnosis.*

*Julie: It made me question my own psychiatrist. I thought what they said was correct as you would if you went into a hospital for an operation you listen to what and let them do whatever. You are more willing to look just google stuff yourself or ask your doctor for a different medication useful. You do more stuff on your own. You become more*

*self-sufficient. You know yourself what you want. It's very important. I am more outspoken in counselling. If I don't want go to the session one day if I'm not feeling well, I will tell them. Well as before I would just do whatever they told me.*

The students described personal agency and feeling empowered by knowledge, language and confidence to challenge not taking any job, leaving jobs that are exploitative and challenging the authority and knowledge of psychiatry and asserting experiential knowledge.

#### **7. 4.2 Collective Agency and Activism**

People experiencing mental distress may struggle to directly influence psychiatry when mentally distressed or when within psychiatric care. They may use the proxy agency of individual or collective Advocacy. Agency can also be exercised collectively according to Bandura (2000): “People do not live their lives in individual autonomy. Indeed, many of the outcomes they seek are achievable only through interdependent efforts” (p. 75).

Collective agency is founded on a shared belief that collectivity can result in change. Mad activism is an organized form of collective agency. The students reported that personal agency has led to collective agency and activism:

*Shona: I felt my voice was being heard and it's made me stronger for my voice to be heard now and I know it will in the future. It's made me stronger to help other people who can't use their voice and for me to help to speak up for other people who have mental health problems that can't get it out. I feel quite active in activism its far and few in between. Its voluntary that I help out. Last year I was involved with conversations for change and that was to speak to the public about what they thought of mental health and it was always in public areas and to give advice and give them some people didn't know where to go for help or support.*

*Eleanor: I've become a lot more informed. I've wanted to be an activist more. I've felt like I am actually doing something rather than sitting in the pub talking about how shit everything is. It ignited fire and passion. I go to conferences, going protests about the ridiculous things the government are doing to people on benefits and doing the research for this course so it continues as activism in education. It's still not spoken about properly.*

Margaret: *I certainly have more interest in mental health. I have read articles, signed petitions and been involved in activism. I want to make things better in society and a lot of mental health is caused by the stresses in society that cause them.*

The students reported finding their voice by being involved in activism, promoting mental health issues, protesting, signing petitions and being involved in this research. The course for Eleanor “ignited fire and passion”.

For students who were already activists, it has changed the activism they are involved with:

Martin: *Always been a bit of an activist. Now my activism is a lot more careful. It is now targeted. I am active by writing academic papers. I participate in mad and autistic communities. It took me a long time for my anger to be channel able into more productive use. My activism is based around a more enterprise model. I am fed up with the voluntary nature of consultation. The voluntary being the token autistic person wheeled out to speak. If we are sitting in consultative meetings we should be paid, need to be paid like the other people around the table.*

Martin has engaged in academic writing and is targeting his actions. Targeted activism relating to race and culture was described by Cleo.

Cleo: *I want to be more active in things. I have noticed that when we talk about health, I am one of the few Africans that talk openly about mental health. It is hush hush. I shouldn't involve myself in Mad History. I will end up like them. I have been told to be careful. I want to be more involved and take it to people who are afraid of the stigmas that you are not coping. It is ok to do it at church but no other places of learning. In the black community church is the answer are we putting ourselves in touch with peers and being able to support each other.*

Cleo described engaging in activism within her own African community by promoting the course and encouraging conversations about madness and reducing stigma. There is a crossover to what is considered collective and political activism.

### 7.4.3 Political Agency and Activism

There is a debate regarding the political impact of service user collective activism within the literature (Sapouna and O'Donnell 2017). In their dialogical article they assert the service user movement's activism focus is on service provision and funding or on critiquing psychiatry and medication.

Targeted activism relating to abolishing the gendered diagnosis of BDP was described as collective and political activism shared by Sandra and Patricia:

*Sandra: The big thing about the course - it linked me straight back into CAPS Advocacy. The film I had helped to make in 2010 was part of the much more than a label personality disorder project. I linked back in with that. I have done loads of things with them over the last few years. I am an educator with LEARN. I help deliver the course. Although it's a Personality Disorder project it's around Borderline Personality Disorder diagnosis. I am one of the trainers. We have linked into Queen Margaret and Napier University. We train people that haven't been to University - anyone that wants to come. That was an immediate thing. I am going down anti-personality disorder diagnosis route. We spoke at a big conference on personality disorders. I am excited that we have been asked to speak at a Personality Disorder conference in London. It's opened up a whole new world to me.*

*Patricia: I stayed involved with the mad history group and was involved in presenting at a Mad Studies Conference in Lancaster. I am going with another student and going to speak at a conference on personality disorders. All the key clinicians all the key professors will be there we are going to say that PD as a diagnosis should be abolished as it doesn't make any sense. I am representing a Facebook group involved in group PD in the bin. We are challenging this diagnosis as a legitimate label. There is a growing tide in challenging the diagnostic. It feels like going into the lion's den. I am still active and involved. It feels challenging but empowering. I am using my Photovoice as the presentation.*

*Sandra: Other things that I have done with CAPS Advocacy are the people's conference and taking stock. Taking stock is NHS Lothian's main mental health conference every year. The People's Conference is for people with mental health problems. It's about getting their voice heard. After taking stock, it's good. We've taken reports to the NHS Lothian Board so it's being fed back into the NHS. Not sure what changes are made. We need to be more careful that our ideas are being fed back into the system.*

The partnership with CAPS was central to many of the activist endeavours engaged in by the students after the course. It was interesting that Patricia was using her Photovoice image to challenge BPD as a diagnosis at a conference. The collective political activism was challenging psychiatry but also engaging in education and influencing policy.

## **7.5 Chapter Summary and Discussion**

The findings suggest that the course has facilitated the generation of new knowledge about madness from people who have experienced it. They also indicate the importance of facilitating “Mad grief” through sharing stories of loss that are frequently subjugated and pathologised. The literature suggests that Mad Studies is a term that is used to embrace the body of knowledge that is informed by and generated by the perspectives of psychiatric survivors and mad-identified researchers (LeFrançois et al 2013). The findings reveal the course had generated knowledge and promoted both agency and activism.

On the course, this knowledge generation about madness has also been influenced by the conscientisation through the sharing of personal and collective experiences of madness and oppression. The Freirean concept of conscientisation involves the development of critical consciousness through a process of reflection, action and dialogue about the individual and collective experiences of oppression (Freire 1970). MPHl is an exercise in critical pedagogy. Critical pedagogy as asserted by Menzies et al (2013) involves radical co-production, circulation and consumption of knowledge. Mad Studies is philosophically underpinned by critical pedagogy and the liberatory vision of Freire that involves: dialogue, participation, voice, historicity of knowledge and facilitating critical consciousness.

Knowledge about madness and Mad Studies facilitated the students to question the dominant biomedical understanding of their distress and explore social understandings of their experiences. Beresford (2013) asserts that Mad Studies is a hopeful challenge to the dominance of the individualised

medical model of mental illness. The students critiqued the dominant biomedical discourse through their experiences and found it unhelpful and harmful. Beresford (2012) advocates the importance of harnessing individual and collective knowledge and experience in order to move to real alternatives to the dominant medicalised understanding of madness. They described the dominant medicalised approaches as not valuing their experiences and subjugating their narratives. Beresford (2016) supports this critique and asserts that expert and experiential knowledge of madness has been historically marginalised. The students did however find a social analysis of their experiences helpful.

The generation of knowledge and conscientisation has led to students feeling both personal and collective agency. Giddens (1984) describes agency as involving knowledgeable agents capable of knowing their social world, who can articulate their experiences within it and the reasons for their responses to that social world. Additional sociological perspectives describe human beings are characterised by agency that involves the ability to influence events and behave independently of societal constraints (Bilton et al 2014).

Within the current discourses of Mad Studies, agency is represented by the assertion that people are experts by experience and that their experiential knowledge has value. Agency is personal, collective and political and is exercised through personal and collective activism. Personal activism has involved challenging their psychiatrist and feeling more empowered in dealing with institutions and employment choices. Being aware of one's agency and feeling empowered have been factors in student involvement in collective activism.

Following the course, students reported that they had engaged with our partner organisation CAPS. They became involved in writing, protesting, educational community projects and attending conferences to challenge the dominant discourses about their experiences. They also challenged sanism by engaging in mental health awareness projects with the public as well as input into training students and professionals. Their activism was focussed on

challenging testimonial injustice (Bondy 2010) by telling their stories of mental distress, “psy violence”, psychiatrisation and sanism. Costa et al assert that there has to be a political outcome from stories of lived experience:

.....Those who reveal their stories to consider doing so in a way that is politically accountable and focused on social justice change. And through this small act of organizing resistance, we inform those that solicit stories that we are now asking, in whose interest? Costa et al (2012, p.99)

There is debate within the literature regarding the political impact of service user collective activism. Sapouna and O'Donnell (2017) assert that the service user movement's activism focuses on service provision; funding and critiquing psychiatry and medication. They suggest there is lack of political activism as a result of limited exposure to ideas, discussions and skills. O'Donnell concludes that “It's kind of an education thing! You need it around you, you need to be exposed to ideas, you need to be able to have discussions and you need to have your skills developed” (Sapouna and O'Donnell 2017, p.528).

Since the course, students who were already activists have focussed their activism on targeting specific collective activism such as BPDIN THE BIN to remove this gendered diagnosis. Others refused to be voluntary activists and focussed on academic papers to promote the mad and autistic communities. Beresford (2013) advocates the importance of the intersection of Mad Studies and practice resulting in praxis. Praxis is defined by Freire (1972, p.99) as: “reflection and action upon the world in order to transform it”. Freire asserts that praxis is not only cerebral but it involves action and reflection. Praxis is generally defined as the point where academic activity is combined with practice to connect with action and change. Beresford (2013) asserts that Mad Studies is about activism that offers an alternative to psychiatry. The students report that the course has had an impact on their knowledge, agency and activism.

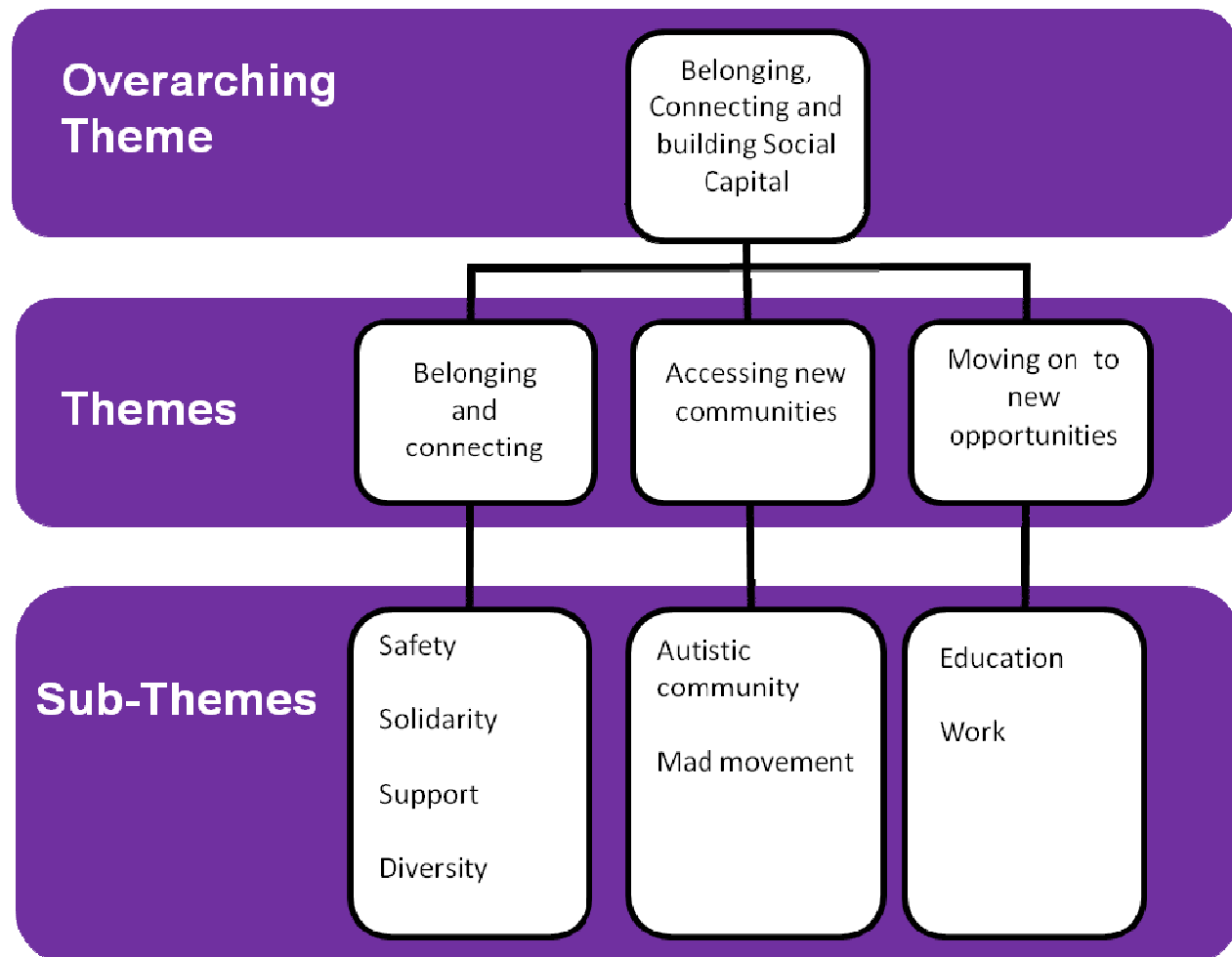
One of the actions of this research was a Photovoice exhibition to which the PAR group invited Scotland's Mental Health Minister. The aim of this was to inform and influence political thinking. The course clearly resulted in individual and collective activism. The literature suggests the actions of sharing experiences, challenging the "psy complex" and its biomedical model need to focus on political outcomes. This outcome is ultimately praxis that has the promise to provide an alternative to the current psychiatric hegemony and discourse. What is clear is that the students are on a diversity of activist journeys facilitated by the MPHl course. This has resulted in the facilitation of counter knowledge, agency and actions. This included their everyday experiences of struggle but is part of a larger emancipatory project of challenging sanism and the "psy complex" and its dominant discourses about madness.

The main aim of the course was to engage the students in activism. MPHl is also a widening-participation course. The students revealed the importance of the social space and social impacts that generated the fourth overarching theme of belonging, connecting and building social capital.



## 8. Chapter Eight: Belonging, Connecting and Building Social Capital

Figure 6: Fourth overarching theme, Belonging, Connecting and Building Social Capital, themes and subthemes.



### 8.1 Belonging and Connecting

There were four subthemes generated under this theme of belonging and connecting the first was safety. This was expressed by Martin:

## Safety

Martin: *It was humbling being with everybody on their various journeys and the group that developed was very special to me - the fact that they had been through that journey in that safe space.*

Shona: *I knew that it was confidential - what happened in class stayed in class. I opened up about everything and I know so did others.*

Martin: *Experience was amazing. Felt safe with the group of people. Energy of the people was gentle.*

Margaret: *I felt valued for my ideas and as a person. I felt comfortable and relaxed.*

The students emphasised the importance of a safe mad space in which there was a sense of understanding and solidarity.

## Solidarity

Being in a space with other mad people was a dominant theme throughout the data referring to a feeling of solidarity on the course.

Julie: *It's easier and you feel more comfortable going in somewhere that's mad.*

Shona: *But I felt very comfortable with the others and at last I knew I wasn't alone. I wasn't alone we all had different aspects of our experiences*

Sandra: *One of the biggest things it was this relief that people actually thought the way I thought - not everybody did - some were the complete opposite. Gosh I am not the only one. All these things I have thought for years and years and people have actually said to me don't be stupid, take your tablets and don't be stupid. Other people are actually saying this and if other people are saying it, there's got to be some truth in it.*

Eleanor: *Networks people knowing that it's just not you against the system and that if you don't have any other opinions about things you just self-internalise everything so you don't ever get to share the fact that you feel guilty for not being fucking part of society enough or you feel shit for having mental health for so long in your life why haven't you fixed it yet. If you meet other people who are experiencing it then that makes you feel less alone. You feel like you have got other people's opinions that are similar. Not feeling so alone makes you feel stronger there's other people with the same general opinion and view being and being informed.*

It was important to the students that the course was a closed space for mad people fostering a feeling of safety and solidarity. The literature suggests intersectional resistance but the results indicate the importance of closed mad spaces. It was clear from the students that providing mad safe spaces is a prerequisite to sharing personal stories and analysing collective struggles. There was, however, a diversity of experiences and perspectives on the course and a diversity of relationships with psychiatric services.

## **Diversity**

Whilst there was solidarity, there was also an acceptance and welcoming of diversity of experiences and knowledge.

*Patricia: We were quite a diverse bunch of people. We had very different experiences of the mental health system. We were all at different stages of our journey in terms of how we felt about our illness, how we felt about our experiences of mental distress, what sort of labels we'd been given, the treatment we'd been given or offered. The vast majority of my peers were still currently using mental health services.*

*Martin: Knowledge gained on the spectrum of experience valued other identities and experience.*

## **Support**

The students highlighted the importance of peer support on the course:

*Shona: I did have the odd support network over the years as it's been a long time that I have suffered. But now I know I have a few avenues I can go for support but also like doing the voluntary research. That is support for me and I am giving something back.*

*Lorraine: It has had a big impact on me not just sort of outside but personally it's changed me. I have become more confident I am getting involved in things I never imagined getting involved with before. It's given me another group of friends that I can trust. Gaining new friends gaining people that understood or had an understanding of where I was coming from was brilliant.*

*Eleanor: Supporting another person was amazing. It's a wonderful feeling and seeing their confidence boosted it humbles you a little.*

The students were not a homogenised group and the results indicate that that was a positive experience. The peer support was also stressed as important and extended beyond the course. The course had facilitated accessing new communities within and outwith the mad movement.

## **8.2 Accessing New Communities**

Students shared that the course had connected them to wider communities.

### **Autistic Community**

*Martin: The shift in identity on the course led to accessing the autistic community. I feel I am part of something bigger than myself.*

### **Mad Movement**

*Eleanor: It's changed me as a person. I've met a lot of new people. There were other things that came out of the course: talking to people online; there was a Mad People's group that started and the meet up. That was really important. When you don't have confidence to go to anything. That was quite easy to go to as you had been on the course. It was folk that you knew. Meeting new similar minds was a good thing*

*Margaret: I go to the Mad History meet ups.*

An important aspect of the course was what happens once it finishes. Martin engaged with a new community reflecting his new diagnosis. CAPS offered ongoing support in the form of Mad History meet ups to keep students connected. This linked people during and after the course and allowed the three cohorts to meet to share and plan actions. This led to new opportunities including involvement in: research, attending conferences, activist projects and writing articles.

## **8.3 Moving on to New Opportunities**

The students described moving on to new occupations including voluntary work, paid work, education, conferences and research.

## Education

*Lorraine: One of the positives is that I am now studying here at QMU. I never thought that would happen. It wasn't until it was stated you could use the credits to study and do it part-time. I had never thought about doing it part-time. I am now in my second year full-time and absolutely loving it, especially doing public sociology that marries with Mad Studies quite nicely.*

One of the aims of the course was to widen participation to education. It was clear from the course had facilitated wider participation within higher education. Two of the PAR group were studying Public Sociology at QMU.

## Conferences

*Shona: I love going along to lectures and conferences and learning something new all the time and also for me to get my voice heard.*

The course and connections with caps had offered opportunities to attend courses within the UK and Internationally. Mehdi (2013) was part of the PAR group and the teaching team of MPH I she reflects on her experiences of MPH and this includes an image of attending an allied health professional course in Finland to promote this work. Students have since attended and presented at Mad Studies conferences within the UK and Critical perspectives conferences in the UK and Ireland. The findings suggest that the course has been a transitional space for wider opportunities. This PAR was also revealed as important to the students.

## Research

*Eleanor: I go to conferences, going protests about the ridiculous things the government are doing to people on benefits and doing the research for this course so it continues as activism in education.*

*Lorraine: The biggest impact is going into doing the University stuff. My hope is to be a lecturer in Mad Studies - a teacher in it rather than a researcher academic. The course has had a big impact on not just me but everybody. It's been eye opening and amazing and yes frightening at times and to push through it is something else.*

Phillips et al. (2017) suggest the research was important to develop skills and build on a new sense of community. "It was important to us for the research to be in keeping with the course by developing people's skills and building on a newfound sense of community". In the discussions within the analysis of the data by the PAR group what was stressed was the importance of the new opportunities as a form of activism. The students' motivations were to create change. There was also an ambition expressed by Lorraine to become an academic. There was also a positive impact on self confidence in relation to work and other occupations.

## **Work**

The students also reported impacts on work.

*Julie: I am currently looking for a job. It's onwards and upwards. It gives you more confidence like doing your counselling, doing your gardening, being outdoors. It gives you more confidence to go and be yourself and do your own thing. I am moving on in a more positive way.*

*Margaret: I am volunteering reading to older people.*

*Lorraine: It has had a big impact on me not just sort of outside but personally it's changed me. I have become more confident I am getting involved in things I never imagined getting involved with before.*

The students reported building social capital. Putman's (2000) seminal critique of the declining social capital in American society defines social capital as:

.....Social capital refers to connections among individuals – social networks and the norms of reciprocity and trustworthiness that arise from them. In that sense social capital is closely related to what some have called "civic virtue." The difference is that "social capital" calls attention to the fact that civic virtue is most powerful when embedded in a sense network of reciprocal social relations. A society of many virtuous but isolated individuals is not necessarily rich in social capital. (Putnam 2000, p.9)

Social Capital was enhanced by the experience of being in a safe mad space that was supportive and connected the students to new communities and opportunities.

## 8.4 Chapter Summary and Discussion

The literature is focussed on the impacts of critical pedagogy and activism. The students, however, reported the course facilitated solidarity, support and the building of new friendships. The safety of being in the class with other mad people was viewed as positive. Gaventa (2006) discusses spaces for change but also the importance understanding the spaces, places and forms.

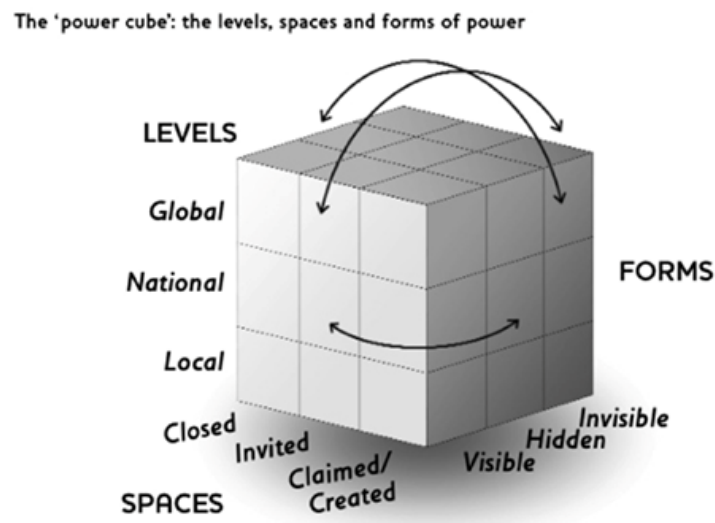


Figure 7: The power cube Gaventa (2006)

The course being held in a University would be described as an invited space. Within the University, however, it was closed space for people with lived experience of mental distress. The creation of safety was an important subtheme from the findings. This indicates that the invited space may not be safe and creating a closed space within it was important. The students were consistent in their positivity about the course being: in a University, having lived experience as the entry requirement, being free and having credits:

*Martin: It was free. It was in a Higher Education. It was interesting because the entry requirements were lived experience.*

*Lorraine: The opportunity of getting credits for it as well was quite important for me.*

*Sandra: That really excited me - the thought of doing something at Uni. The fact that I didn't need any qualifications other than my own experiences with mental health.*

It was clear from the students that providing mad safe spaces is a prerequisite to sharing personal stories and analysing collective struggles.

In relation to social capital, there was a dichotomy of being in a University and a closed space. Students reported that the course had facilitated access to the mad movement. What is important in relation to the findings are Putman's (2000) ideas on bonding and bridging social capital. He asserts that bonding social capital happens between people who have a commonality and results in support and reciprocity but can lead to a narrower self-identity. Bridging social capital involves people who are not from our networks and can lead to accessing external assets, facilitate information diffusion and generate broader identities. The students reported the building of bonding social capital that resulted in collective experiences and solidarity. They, however, also reported that the course had impacted on bridging social capital with students going to University, conferences, engaging with new communities and work.

The findings suggest that the facilitation of a closed space within a University with a mad-identified community expanded social capital as a result of safety, support and new friendships. In addition, students became involved in more expansive occupations out with the mad community and were able to utilise their assets, expand their identities and build social capital. Interestingly they also diffused their mad knowledge and narratives within these new networks as activist endeavours. The course had aimed to widen participation. The research reveals that the participation went beyond the MPHl course to engaging in courses within QMU in Public Sociology.



## **9. Chapter Nine: Conclusion**

MPHI is a widening-participation course within QMU that is free and for people with lived experiences of mental health issues. The course is a Mad Studies critical pedagogy project. The course was co-produced and co-delivered by academics, partners from CAPS and people with lived experience of mental distress.

This study aimed to explore the experiences and impacts of being part of a Mad People's History and Identity course and the relationship between critical education, activism and emancipation. It also aimed to explore how PAR can contribute to the advancement of mad people's knowledge and the promotion of mad activism and Mad Studies.

The research was designed and executed by the students as part of a PAR group that consisted of four students, two partners from CAPS and the author of this thesis. A dialogical approach underpinned the PAR methodology. Data was generated using peer interviews. A total of nine students including the students in the PAR group were interviewed. The data was analysed collectively using generative thematic analysis. The actions decided by the PAR group were the creation of a Photovoice exhibition and the production of a film. The main aims of the actions were to promote the voices of the students in relation to their personal mad history. It was also to create narratives and visual data as an ongoing history of the experiences and impacts of being on the MPHI course and the experience of madness.

The findings suggest that the course had resulted in positive experiences and impacts. There were positive impacts on: identities, knowledge, conscientisation, agency, activism, solidarity and social capital. But the impacts are related and a continuum of stages in the road to different levels of activism. This will be explored under each finding.

Identities had been explored and changed by the course. The students' responses to an individual mad-identity reflect the debates within the literature. For some it was empowering but for others it was associated with

stigma and the “psy complex”. Labelling and abuse from others impacted on the reappropriation of a mad-identity. The findings indicate that mad as an identity is complex, diverse and personal. Whilst rejecting mad as a personal identity, the students expressed a clear position on the importance of the reappropriation of the term mad as a collective political act and an activist stance. Students who were activists within the mad movement or part of other social movements, such as the Gay Rights movement, embraced a mad-identity more comfortably as an individual and collective political act. Sharing the same experiences was more important than identifying as mad.

The findings suggest that the course had a positive impact on how the students felt about their own identities. The course had facilitated a positive change in self-perception of identity. They were able to challenge the negative psychiatric and societal labels they had received from others. They were also exploring identity in relation to gender, race and sexuality. The research did reveal issues in relation to intersectionality of madness and race. The ethnocentricity of the course and this research need to be explored and addressed. Cleo was the one BAME voice who indicated the exclusion of her community from services and this course.

Students reported that they were reclaiming lost identities and had embraced new identities beyond their medical diagnosis. These included: ‘activist’, ‘neurocosmopolitan citizen’ and mad black artist. Positive self-determined identities were an important impact of the course and an important stage towards personal empowerment and exercising agency.

The exploration of their own mad history through the discussions in class and the Photovoice project had been an important, if at times traumatic, part of the course. There was a distinction between the students who described their experiences of mental distress and those who revealed the distress and harm they had experienced through psychiatrisation. The findings indicate that the course facilitated an exploration of the students’ experiences of mental distress and psychiatrisation. This exploration of the individual and collective experiences of trauma, distress, harm and oppression raised

individual and collective consciousness about the experiences and oppression experienced collectively within the “psy complex” and society. There was a focus on female gendered abuse and violence within psychiatry and society. The findings are consistent with the literature regarding the abuse, trauma and medicalisation of trauma that women have experienced within the “psy complex”. It indicates a wider problem of sanism and sexism within society that results in referral to psychiatry and being psychiatrised. They reveal the gendered impacts of the “psy complex”. This results in a biomedical response to women’s distress. This distress results in contested diagnosis, such as BPD, being applied that result in stigma and isolation.

The need to collectively challenge sanism and sexism was highlighted by the students as a more important political act than reclaiming mad. The students challenged the binarism of a world where there are the sane, the insane and the mad. This is an interesting finding as the Mad Studies literature contains debates about the main purpose of the discipline. This ranges between reforming or dismantling psychiatry to a wider revolution of challenging sanism within society and all its structures.

The students reported the building of bonding social capital that resulted in collective experiences and solidarity. They, however, also reported that the course had impacted on bridging social capital with the students going to University, conferences and engaging with new communities and occupations. The involvement in this research was raised as important for the PAR Group in relation to skills, confidence and one student being employed as a researcher. Three of the nine students engaged in Sociology and Psychology courses

The findings suggest that the facilitation of a closed space within a University with a mad-identified community resulted in safety, support and new friendships that increased social capital. In addition, students became involved in more expansive occupations outwith the mad community. They were able to utilise the assets of new occupations, expand their identities and build social capital. Interestingly, they also diffused their mad knowledge and

narratives within these new networks. As a widening-participation course, this is an important impact for the students with many of them finding teaching; studying and presenting at conferences connected them to support and activism.

The findings suggest that the course has facilitated the generation of new knowledge about madness from people who have experienced it. This mad knowledge was facilitated by consciousness-raising through the sharing of personal and collective experiences of madness and oppression and critiquing the Mad Studies literature. Knowledge gained about madness facilitated the students questioning the dominant biomedical understanding of their distress and explore social understandings of their experiences. They described the dominant medicalised approach as not valuing their experiences and subjugating their narratives and histories. The generation of knowledge and conscientisation has led to students to exercise personal, collective and political agency.

Personal activism involved challenging their psychiatrist, feeling more empowered in dealing with institutions, and making employment choices. It is important to acknowledge personal activism reflects the daily struggles of people's lives and may occur in private settings. These created spaces are as important as public activism.

Being aware of one's own agency and feeling empowered have been factors in student involvement in collective activism. The students reported that following the course, they engaged with advocacy organisations such as CAPS. They became involved in writing, protesting, educational community projects and attending conferences to challenge the dominant discourses about their experiences. They also challenged sanism by involvement in mental health awareness projects with the public and training students and professionals. Students who were already activists have focussed their activism, targeting specific collective actions such as challenging BPD as a diagnosis (BPDIN THE BIN).

Students reported that the course has facilitated the sharing of their everyday personal and collective experiences of struggle. They have shared their own resistances to oppression caused by sanism. The literature suggests the collective actions of challenging the “psy complex” and its biomedical model are important. There is, however, a debate within the literature that asserts that Mad Studies needs to focus on political activism and ultimately praxis to provide an alternative to the current psychiatric hegemony and discourse. What is clear is that, as a result of the MPHl course, the students are on a diversity of activist journeys. Some started prior to the course and others whose actions have been reignited and focussed by the course. Other students have found their voices. This has been facilitated by creating a closed space that produced counter knowledges, fostered agency and actions. The actions included their everyday experiences of struggle. The findings clearly identify a relationship between MPHl and activism that is diverse, personal and on a continuum.

Have the findings revealed that through fostering activism, the course has resulted in emancipation? The everyday struggles of the students and their mad histories of distress and oppression are part of a larger emancipatory project of challenging sanism and the “psy complex”. The “psy complex” is a powerful institution that has produced the dominant discourses about madness for decades. It is also located within a wider sanist society. MPHl is part of a struggle of epistemic resistance through revealing subjugated narratives and the creation of counter-narratives and knowledges about madness. This has led to activism that challenges the knowledge and practices of the “psy complex” and sanism within society.

The research has produced new knowledge about the experiences and impacts of Mad Studies as a developing critical pedagogy not as advanced as the critical pedagogies of other social movements. Self-determination, knowledge and conscientisation are part of a process to facilitate agency and action as part of a larger struggle for emancipation. It is hard to predict what the impacts of this collective experience and actions will achieve. This

research has provided a rich amount of data to support and promote the course as a political activist space in the future. The research data and actions of the research are adding to the body of knowledge about madness from the perspectives of the people who have experienced it.

The impact of this research on theory and practice is an important consideration of this research. What is also important is to explore the impact of the PAR methodology of this study to both the experience of the MPHI PAR group students and the knowledge produced. The following, and final Chapter Ten of this thesis, addresses these points.

## **10. Chapter Ten: Reflection and Actions**

### **The Complexities of CPAR**

PAR research is complex and messy. Cook (2009) describes the importance of acknowledging this complexity and the importance of engaging in the messiness of this research methodology to ensure rigour in interpretation and method:

..... The honest embodiment of the mess, its process, practice and purpose, will help researchers understand the drivers behind changes in thinking and transformational action in enquiry; how to reach the 'messy turn'. If an indicator of our successful work as action researchers is the integration of the development of practice with the construction of research knowledge, then we must provide honest accounts of that process and incorporate mess as an integral part of a rigorous approach (pp. 289-290).

CPAR as a methodology offered opportunities and challenges in this research project. This last Chapter will explore the complexities of this CPAR and critique if we have been able to stay true to the philosophy and values that underpin CPAR. It will also explore the perspectives of the PAR Group on this methodology. The centrality of the community issues and participation in all aspects of the research is at the heart of PAR (Kindon et al 2010, Fine 2008). It also has the values of democratising research and knowledge production, emphasising dialogue and negotiation, and is aimed at socially just processes and outcomes (Fals-Borda (1996). (Kindon et al 2010) stress the importance of: "critically informed PAR to facilitate the intersections between theory, practice and politics between participants and researchers" (p.3).

### **Centrality of User/Survivor/Mad Perspectives and Participation**

This CPAR combines the principles of participatory action research, Mad Studies, critical theory and survivor/ user research. It advocates that user/survivor/activists/mad people must be actively involved in all stages of Mad Studies (Costa 2014). The extent to which this ideal can be achieved is

not unproblematic and was a challenge for this doctoral level research. The choice of exploring the MPHl course was initiated by the author and partners of MPHl who included user/survivor/mad MPHl students. There was full participation in all aspects of the research until the later stages of analysis in which the author synthesised the themes into over arching themes to reflect the themes that the PAR group had generated.

The actions were collaboratively agreed and generated. The Photovoice exhibition was organised by the PAR group who participated in speaking at its launch. The film was designed by the PAR group, recorded by the author and a student film maker. The PAR group participated in the film and edited it. The dissemination of the results will invite participation from the PAR group. This has already been initiated by our involvement in a conference presentation in Cork, November 2018 and the contribution to a book Chapter (Ballantyne et al 2019). The centrality of participation and the experiences of PAR were reflected on by three of the user/survivor/mad researchers:

*Patricia: During the initial meetings we had opportunities to learn about research methods and to gain an understanding of the key principles of Participatory Action Research as well as being involved in developing the research proposal and reflecting on ethical considerations. Additionally, myself and other student members of the PAR research team were also research participants as we were to be interviewing each other as well as other students on the Mad History courses. As a research group we were able to be involved in collective decision making about the research aims and protocols as well as writing questions for the interview schedule and developing a framework for analysing the results, and participating as a group in analysing the interview data.*

*Eleanor: My experience of PAR was overall very positive. I feel that PAR was the best type of research to use as the MPHl course was very immersive, emotional and challenging. I think and feel we achieved a very holistic evaluation as the students were able to be as critical and honest as they wished. We also filmed the interviews, so they could be reviewed and then we transferred the themes we sieved to the surface onto post-it notes. This was a good physical way to see all the themes though practically annoying. I also feel that using students as interviewers hopefully helped people feel comfortable and open. This thorough, reflective and critical approach will help the course stay moral and inclusive and enable it to evolve 'Sane in insane places'.*



*Shona: PAR-research at QMU was a very useful experience for me to participate in. I feel strongly it should be ongoing at least every 2 years on the MPHl course. I felt empowered after seeing the outcome of our research and the many people that contributed to this important work.*

Doing PAR is full of surprises. While discussing the interviewing of the students, Patricia suggested that the people in the PAR group who were not students and not mad, should not carry out the interviews and that they should be peer-led. My first reaction was one of feeling excluded from the data collection. In my diary I wrote that “this didn’t seem like partnership” (diary extract). I reflected that to exclude us was indeed a positive reflection of the ownership of the research and the empowerment of this group to take the lead when appropriate. Peer interviewing made perfect sense to me when I watched the films. It was a relaxed dialogue between people who knew exactly what the issues were and gave authentic empathy and support to each other but also interrogated the responses with a shared language and non-judgemental approach. It aligned with the values of PAR of “Working with people as full partners and researchers” (Fals-Borda 1996, p.4) and the perspectives of the community being valued and acted upon. Wadsworth (1998) describes PAR as researchers and participants working together to examine a problematic situation and decide on action to change it for the better which results in emancipatory outcomes.

### **Emancipatory Outcomes**

Has PAR successfully contributed to understanding the relationship between engaging in MPHl, activism and emancipation? I assert that it has facilitated a democratic exploration of the experiences of the MPHl course and its impact on the diverse activist journeys of the MPHl students. The everyday struggles of the students and their mad histories of distress and oppression are part of a larger emancipatory project. This project created a critical space to facilitate a counter discourse, promote experiential knowledge and foster resistance through activism. The research supports that MPHl offers a political activist space. Through this PAR significant steps towards different forms of liberation have been achieved through conscientisation and

involvement in creating activist actions. This falls short of ascertaining that the research itself is liberating.

The Photovoice exhibition shared visual and narrative data and invited a diversity of guests, including the Scottish Mental Health Minister and leaders in mental health services. Over the next five years, it is planned that we will add to this visual history with regular exhibitions of the students work. The exhibition and film aim to promote the voices of the students both about the course and also about their experiences of distress, psychiatrisation, madness and resistance. The film has still to be shared with audiences. The course and this research are generating an ongoing history of a MPH community. It is hoped this research experience may facilitate further research involvement by the students as partners in PAR projects relevant to what they want to promote as a mad community. In the future, this may lead to research that is survivor/ user controlled which is part of an ongoing struggle for positive political change. One of the students has recently been employed as a researcher whilst another three students are engaged in University degree courses and will be generating research. The PAR group have engaged in research that has provided skills and confidence of themselves as researchers. This may lead to activism through the collective sharing of the results in literature and at conferences. I will continue to collaborate as an ally with the PAR group to help disseminate our findings through presentations and publications.

By providing a broader critical understanding of the complexities of the experiences of madness, the findings from this research may be useful in informing practice. It may assist practitioners to explore their attitudes about the importance of experiential knowledge. This may impact on widening the inclusion of user/survivor knowledges in practice. Promoting the course, by sharing the research to different audiences, may engage and connect people experiencing mental distress to this MPH community. The partnership delivers educational input to: Occupational Therapy, Music Therapy, Art Therapy, Psychology and Sociology students. The challenge is always

reaching a wider audience in order to challenge the dominant discourse about madness. We have a regular input to The City of Edinburgh Council Mental Health Awareness course. We would aim to collectively share this research in the aforementioned spaces. PAR raises opportunities and challenges for a novice Doctoral Researcher, the first of which is about identity.

### **Not being Mad: Outsider/Insider dichotomy**

Kindon et al (2010) acknowledge that within the University, academics engaging in PAR need to negotiate two conflicting social worlds. This research involved a mad-positive academic who is not mad-identified. As an academic, I had the privilege of working with this group of user/survivor/ mad MPHl students on the MPHl course. I was now involved with MPHl students and partners in designing research and exploring their experiences of the course and wider issues. The identities of the PAR group were not a focus of discussion, possibly because we already built a trusting relationship with each other. The author and one of the partners in PAR does not identify as user/survivor/mad whilst the rest of the PAR group and all the participants do. There were times during the research that the PAR group felt in a very secure space and there was a connection and solidarity amongst us that acknowledged and accepted our diverse identities.

Participating in the research was an extension of the tensions I have felt being part of MPHl as a privileged academic. I have made mistakes of not sharing platforms initially and have been conscious of making sure that I included the group in all aspects of sharing this work. I have felt the stress of being responsible for the research and not wanting to let the group down. I still feel uneasy consuming the experiences and data from this project as an outsider. I am more aware of when my skills and knowledge are helpful and when they are not required and more accepting of my privileged position.

Durham Universities (2012) ethical guide for Community based Participatory Research (CBPR) asserts that as the boundaries between researchers and participants become blurred, this creates additional ethical challenges. In my

experience, this blurring of boundaries was positive. We shared commonality in being part of the MPHl course; experiencing oppression and wanting to challenge oppression. I have had my own experiences of discrimination as a working class, Catholic woman born and raised in the West Coast of Scotland. At times in my life, I have experienced stress and distress but never had this medicalised nor had personal contact with psychiatry. I have also worked within psychiatry and social work for twenty years and witnessed the oppression of many groups within society. Despite this personal and professional history, I have also had the privilege of being ignorant of the embodied experience of mental distress, psychiatric violence and psychiatrisation. Most of the challenges openly discussed were from the non-user/survivor/mad members of the PAR group. Working as an outsider with this community has been both a privilege and an unsettling relationship.

### **Building Respect, Trust and having Personal Integrity**

Building trusting relationships with mutual respect and personal integrity in is central to PAR (Durham University 2012). Fals-Borda (1995) asserts that: "PAR is a purposeful life-experience" (p.4). We started from the strong position of already knowing each other, so had already developed respect and trust to a degree. One of the important factors was allowing time to develop this relationship. Ensuring everyone was able to contribute in all stages of the research was important.

PAR is underpinned by a philosophy of collaborative active learning (Durham University 2012). It has been one of the highlights of my academic career and I have learned and grown significantly from my involvement.

### **Novice PAR Researchers: Learning together**

Being novice PAR researchers often meant we were learning together. We attended the same PAR training course at Durham and shared the input from both of my supervisors on interviewing, analysis and PAR. On reflection, I think more training on analysis would have been useful. Learning together

was a positive mutual experience. Perhaps being novices together had a positive impact on the balance of power and participation. Time constraints and the limited resources open to a Doctoral student were challenging. However, we rejected an initial short timescale and committed to taking the necessary time to ensure maximum involvement and quality research. More experienced PAR researchers were available to guide us through our learning.

### **The Role of the Academic in PAR**

“What is my role in PAR?” was a question that occurred for me throughout the research. I was uncomfortable in the role of expert and at times was reluctant to bring my knowledge to the table for fear of dominating the group. I struggled with when to intervene and when not as I was a novice PAR researcher. Am I an activist aligned with this social movement or a facilitator of activism? This important question pervades the literature regarding the role of the academic researcher in PAR. Is it one of facilitation, of co-investigation or a second position that adopts the advancement of knowledge? Jacques et al (2013) assert that engaged researchers support the experiential knowledge and reflective action of participants coping with real life problems. However, they should also pursue theoretical reasoning within the research and be transparent about the identify tensions within the project. This can be a limitation as some Mad Studies literature advocates user led/controlled research. As an academic, I was acutely conscious of not taking over the research and at times this held me back from contributing throughout the research. I am unsure if I always got the balance right.

### **Power and Privilege**

The power dynamic in research is important but particularly in PAR which aims to be democratic and share power. Kindon et al (2010) assert that whilst they seek democratic processes and socially-just outcomes, they can result in marginalisation. Kesby et al (2010) assert that power is at the heart of PAR. It can empower or involve the abuse of power such as domination,

coercion, inducement, manipulation and conceding authority to the academic researcher. I accepted an invitation to talk at a Ragged University event and gave an overview of the course. This was followed by one of the students coming on the stage and talking about her perspective which had not previously been discussed. I wrote in my diary: "I am not part of this tribe". I was describing feeling, which entered my consciousness throughout the research, of being an outsider and an imposter who didn't belong. I later reflected "I was really flattered to be asked to this event. I should have had the humility to share the space with the students. I was also so anxious about this first presentation that this did not occur to me at the time (diary extract). My position also reflects that I am rarely excluded in any situation and that my whiteness, power and privilege as an academic can be taken for granted. Conscientisation for the academic researcher was an important part of the PAR process. Acknowledging power and privilege is important and using it to benefit the community you are working with is integral to PAR. Your aims should be focused on making a difference through collective decision making and action (Durham University 2012).

### **Dialogue, Dealing with Conflict and Collaborative Decisions**

In a diverse group, there will inevitably be disagreements and discussion and we were no exception. Durham University (2012) stresses the need for being open to challenge, change and dealing with conflict.

There is a section on the ethics form that asks if the participants have mental health issues. This generated debate within the PAR group about when, if ever, people with lived experience of mental health issues are considered to have this label. The PAR group identified themselves as mad activists. The remaining participants were diverse in how they identified themselves from psychiatric survivor, neurodiverse to mad activists. We decided that the research involved people who had experiences of mental distress but they may not identify with the label of having mental health issues or being vulnerable, so we left it blank. This did not reflect our ethical decision to provide support to all participants if required. This was an interesting debate

about who decides your vulnerability and how research processes still have traditional ethical processes embedded within them.

Switching from being the lecturer to a co-researcher throughout the research was a transition for me and the PAR group. We didn't always agree on the design of the research. Throughout the process, the research proposal was frequently debated and changed. One of the students wanted to challenge the University to have a permanent Mad Studies course under new legislation. The politics of the University and the ambitions of the group had to be explored and discussed. We had limited time to conduct the research and the actions had to be achievable within the allotted timescale. We had already secured a space for the course within the University for a period of five years (with another five years guaranteed). Within a University there are no guarantees for security in any course. The University was supporting this work which was funded by NHS Lothian. This action did not appear appropriate at this initial stage of developing our profile within this space. The rest of the group agreed.

In June this year I found an article in Asylum magazine written by two members of the PAR group and one participant. We had previously agreed that all outputs would be collaborative – examples of which are: joint presentations at an international conference and two mental health awareness courses; joint teaching of OT students; and co-authoring a Chapter in a Public Sociology book. Consequently, it appeared to me as if our collaboration agreement was one-sided. I discussed this with a peer, reflected on it and decided to send an e-mail congratulating them on their success. The University customs and agreements had been disrupted by my co-researchers and my expertise not required. It made me reflect on how rare it is for me to be excluded and that disruption is an activist act that should be supported. It also stresses the importance of dialogue about ownership and dissemination within PAR.

## **Being Human**

Central to PAR is recognising each other's expertise and limitations. We often started sessions asking how we all were and discussed life, politics and madness. Conversations about our life experiences, experiences of distress, psychiatrisation, abuse, loss were part of our in designing the research. I had had some difficult times over the last two years some of which I shared with the group. I woke one morning with chest pain, ended up at A & E, was diagnosed with work-related stress and signed off work for 14 weeks. Following this, the group all sent me e-mails and Eleanor arrived with flowers. Whilst feeling guilty about interrupting the research, I was reassured and supported by the group and felt able to stay off despite a feeling of letting them down. Lorraine shared that, after suffering a loss, she had come to the session as the banter cheered her up. Shona talked of forcing herself to come to the group as it was important get her through her bad days. We also laughed, shared and supported each other. The relationship didn't appear blurry but supportive and essential to work effectively on designing the research.

My reflections above are from a position of privilege and my attempts to be a mad-positive ally of this work. Being an outsider is both a privilege and an unsettled relation as described by Church (2013a). I have not always got this balance right. The experience of Church (2013b) has resonated with me on knowing when to be visible and when to be invisible. It is important to know when to bring your expertise to the table to be useful to the project. Cresswell and Spandler (2012) critique of the engaged academic also resonates with me. I have found this work at times to be: time intensive, consuming, challenging, de-skilling, exhausting and stressful. This is in the context of completing a Doctorate as well as doing a demanding, full-time job. I have more regularly found the partners and students inspiring, humbling, knowledgeable and supportive and I wouldn't wish to change my involvement with the project.



## Conclusion

PAR in this project was messy, time-consuming and posed challenges for both the PAR group and myself. It is my analysis that we aimed for maximum participation and achieved this until the last part of the analysis. We built a trusting, respectful relationship that facilitated dialogue and had space for exploring difficult issues and disagreements. We worked collaboratively and with consensus around our choices and decision-making process. We related mostly as human-beings with skills and limitations, who require support. We brought our joint knowledge and expertise to this project. We were aware of difference, power, privilege and the constraints of being novice PAR researchers. We collaboratively decided action with the political aim of promoting the experiences, knowledge and wider issues of this community who had been part of the MPHl course. We demonstrated values of inclusion by widening our data generation and actions to the wider cohort of students and partners. We learned together and continue to learn from each other through ongoing collaborations. Small research projects such as this Doctoral PAR should not overestimate emancipatory outcomes. It should also not underestimate the importance of preserving and promoting the MPHl course, as a political activist space, through providing evidence of its impact. It is also important to acknowledge the importance for the PAR participants of generating knowledges about their experiences. Philips et al (2017) article on the research suggests the importance of PAR by asserting:

.....We wanted to break down the gap between researchers and those being researched, just as the course aimed to blur the lines between lecturers and students, and we thought it vital to bring the message of the course to people in other parts of the university.

The importance of a critical approach underpinning PAR is reflected by Eleanor who suggests that *“this thorough, reflective and critical approach will help the course stay moral and elusive and enable it to evolve ‘sane in insane places’”*.

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## **12. Appendices**

## Appendix One: MPHI Module Descriptor

### Module Descriptor

Title	Mad People’s History and Identity			Code (if known)
SHE Level		Semester & Mode of Study	Semester two Full time	Credit Rating  SCOTC AT: 20 ECTS: 10
SCQF Level	7			
Module Co-ordinator		Elaine Ballantyne		
Module Team		Kirsten Maclean, John Hughes, Nyla Mehdi, Gus Niven,		
Pre-requisites		Lived experience of mental health issues		
Co-requisites				
Prohibited Combinations				
<p>Module aims:</p> <ul style="list-style-type: none"><li>• To present a history of mental health from the viewpoint of people who are deemed to be “mad” or to have “mental health issues”</li><li>• To situate the lived experience of mental health issues at the centre of the curriculum</li><li>• To harness students identities as “experts by experience”</li><li>• To enable students to situate their own lived experience of mental health issues within the wider socio-cultural and historical contexts of local, national and international activism</li><li>• To enable students to think critically about mental health and the mental health system</li></ul>				

<b>Learning Outcomes</b> On successful completion of the module the student will be able to:		Assessed in this module	A	B	C	D
L1	Explore and situate their own experience of mental health and/or the mental health system within a wider historical perspective, and see themselves as “experts by experience”.	Yes: formative and summative	*	*	*	
L2	Identify key moments in the history of activism by people with mental health issues, within local, national and international contexts.	Yes: formative and summative	*	*	*	
L3	Analyse and debate the intersectionality of mental health and the social construction of gender, sexuality, race and social class.	Yes: formative and summative	*	*		
L4	Describe and evaluate the dominant social and medical models of mental health.		*	*	*	*
L5	Describe and evaluate issues of identity and power as they relate to mental health.	Yes: formative and summative	*	*	*	*
L6	Demonstrate an elementary understanding of relevant sociological theories and concepts.	Yes: formative and summative	*	*	*	*

A – Knowledge and Understanding

B – Intellectual Skills

C – Practical Professional Skills

D – Transferable Skills



**Learning Experiences**

The module will engage the student in the following types of learning experiences: Lectures, tutorials, seminars and workshops

Visiting lecturers with a lived experience of mental health will be at core of the learning experience in conjunction with self-directed and directed learning activity.

Final assessment will be Photovoice project

Lectures & Seminars 20 hours

Directed Study 90 hours

Independent Study 90 hours Total 200

**Assessment Pattern****Formative**

Evaluation of knowledge, skills and attitudes through contribution to discussion?

Discussion postings on blackboard

**Summative**

Final project – Photovoice project

1000 words written narrative and theoretical framework

**Can this Module be Anonymously marked? Yes review No please provides an explanation.**

No presentation.

**Content**

- Narratives of lived experience situated at core of curriculum
- Lived experience situated as valid academic knowledge base
- Challenging dominant thinking around mental health
- Introduction to concepts of language, labelling and “othering”
- Introduction to concepts of power and privilege in context of mental health
- Introduction to concepts and theories of social change, diversity and equality
- Intersectional discourses on sexuality, gender, race and class
- History of activism and social movements as they relate to mental health
- Community Development
- Critical thinking
- Reflection

### **Main Texts:**

LeFrancois et al (2013)“Mad Matters: A Critical Reader in Canadian Mad Studies”, Canadian Scholars Press

CAPS (The Consultation and Advocacy Promotion service) (2010) Oor Mad History: A Community History of the Lothian Mental Health service user movement. Edinburgh: Living Memory Association#

<b>Other relevant details</b>	
A dedicated WebCT programme is available for student directed learning and discussion of key concepts related to this module	
Signed	Date
<b>Registry use only</b>	Date received

## **Appendix Two: Semi structured interview schedule**

1. What motivated/attracted you to apply to the course?
2. What are your thoughts about reclaiming the word “mad” in this course?
3. How would you describe your experiences of being on the course?
4. Can you describe the Photovoice image you selected for your assignment and why you chose this image?
5. Has being part of this course had any impact on you in relation to?
  - (a) Identity
  - (b) Involvement in activism
  - (c) Empowerment
  - (d) Participation in new activities
  - (e) Support networks
  - (f) Other

### **Appendix Three: E-mail to recruit research group**

Hello,

I am writing to inform you of a paid opportunity to engage in research about the experiences and impacts of being part of this course. If you are interested in being trained in research and carrying out research with a team from the module please contact me directly. We are looking for two students.

We are also hoping to recruit you as graduated students to get your perspectives. If you would be happy to be interviewed about the course please get in touch.

It is hugely important that in order to develop this work and secure funding that we can demonstrate its importance and impact.

Warmest wishes to you all.

Elaine

Elaine Ballantyne (Msc,Bsc,DipCOT,SROT)

Senior Lecturer in Occupational Therapy

Senior Fellow of The Higher Education Academy

Queen Margaret University

Tel (0131 474 0000)

PgDip/Msc OT website

<http://www.qmuc.ac.uk/ot/FAQ.htm><http://www.qmu.ac.uk/>

## **Appendix Four: E-mail to recruit interview students**

Hello folks,

Thank you to everyone who contributed to the exhibition it was a great success. We are carrying out interviews as part of our research into the experiences and impacts of being on the Mad People's History Course. I attach an information sheet about the interviews. They will take place on two days Friday the 21<sup>st</sup> April and Monday the 1<sup>st</sup> of May. If you would be interested in being part of this please let me know and we can arrange a time for you to be interviewed.

Best wishes

Elaine

Elaine Ballantyne (Msc, Bsc, DipCOT, SROT)  
Senior Lecturer in Occupational Therapy  
Senior Fellow of The Higher Education Academy  
Queen Margaret University  
Tel (0131 474 0000)

## **Appendix Five: E-mail to recruit Photovoice participants**

Hello and belated New Year wishes to you,

I would like to invite you to an exhibition of the Mad Peoples History course students work over the last three years here at Queen Margaret University on the **23<sup>rd</sup> of March at 4.15pm**. The exhibition will be a celebration of the student experience and success. It will aim to promote the histories of the students and also promote the course. I would like to include anonymised (unless otherwise instructed by you) the image you submitted as part of your assignment in the exhibition.

There will be a short presentation by students talking about the experience and impact of the course, and why they chose the image they did. The audience will be students and supporters of the course. There will be the presentations at **4.15pm** and then wine and snacks about **5.15pm**.

**Would you be happy with your image being part of this exhibition?**

**Would you be happy to speak for 5 mins at the event?**

I would love for you to come regardless if you want to exhibit or speak at this event. It would be lovely to catch up with you. If you are travelling far we may be able to help with train fares. The images are fantastic and it would be great to include your work in this exciting event. Let me know what you think and I will send out official invites soon.

Best wishes

Elaine

Elaine Ballantyne (Msc,Bsc,DipCOT,SR0T)

Senior Lecturer in Occupational Therapy  
Senior Fellow of The Higher Education Academy  
Queen Margaret University  
Tel (0131 474 0000)  
PgDip/Msc OT website  
<http://www.qmuc.ac.uk/ot/FAQ.htm><http://www.qmu.ac.uk/>



## **Appendix Six: Photovoice images from the exhibition**

### **Appendix: Photovoice images**



Embodied experiences of Mental Distress



Loss of Identity



Mad-identity

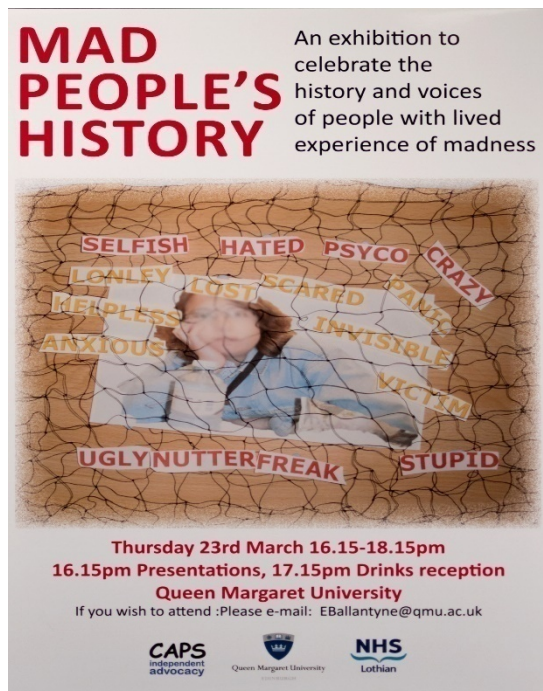


## Experiencing Psychiatisation





## Appendix Seven: Photographs of the Photovoice Exhibition



Flyer



Mental Health Minister and Principal

## **Appendix Eight: E-mail film participants**

Hello folks,

I hope you are all doing well and praying for some sunshine. As part of the evaluation of the Mad People's History course you attended we are planning a film to promote the experiences of being on the course. The filmmaker can come to you or you can come here to be filmed. It will only be used selectively to promote this work and your voices. August is the preferred month to film. Let me know if you would be interested in being part of this short film it is approximately 10 mins long.

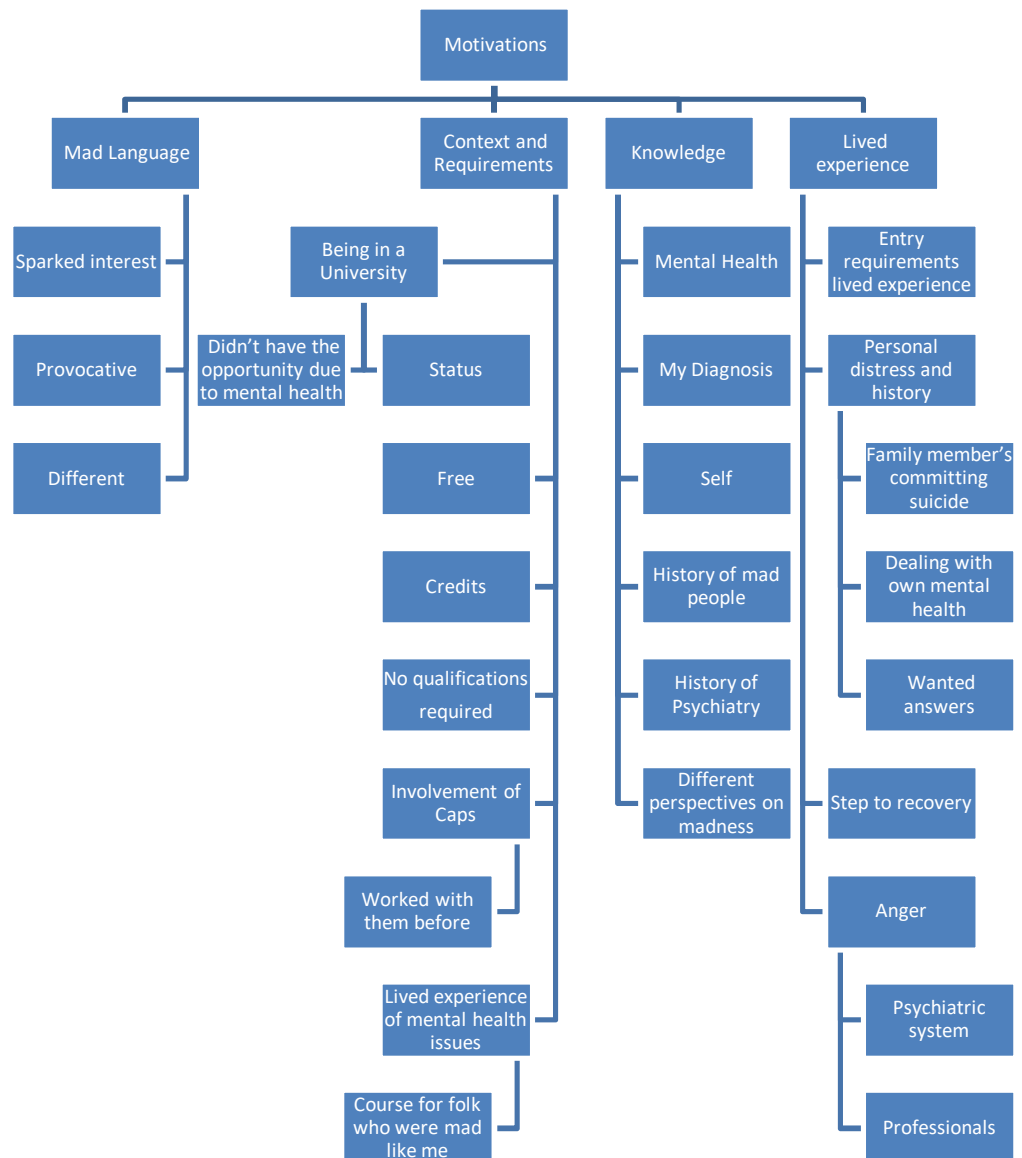
Best wishes

Elaine

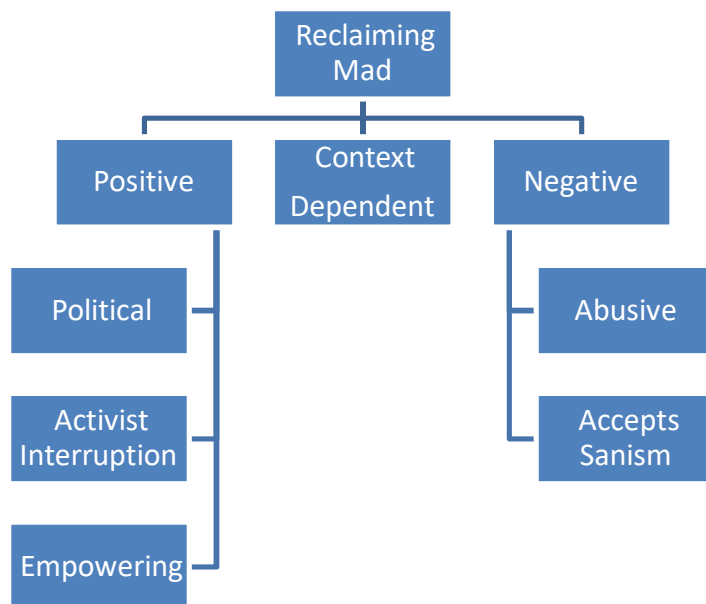
Elaine Ballantyne (Msc,Bsc,DipCOT,SROT)  
Senior Lecturer in Occupational Therapy  
Senior Fellow of The Higher Education Academy  
Queen Margaret University  
Tel (0131 474 0000)

## **Appendix Nine: Film**

## Appendix Ten: Initial themed maps from the data analysis

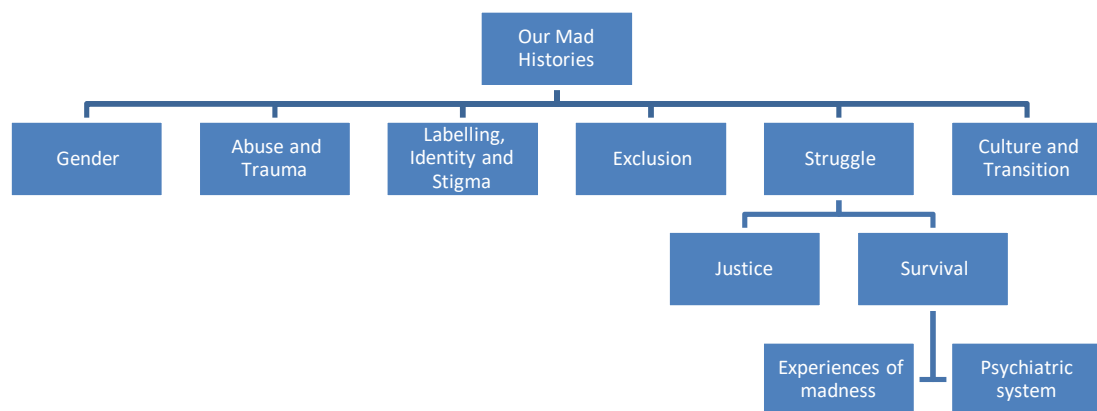


Themed map one: motivation to attend the course

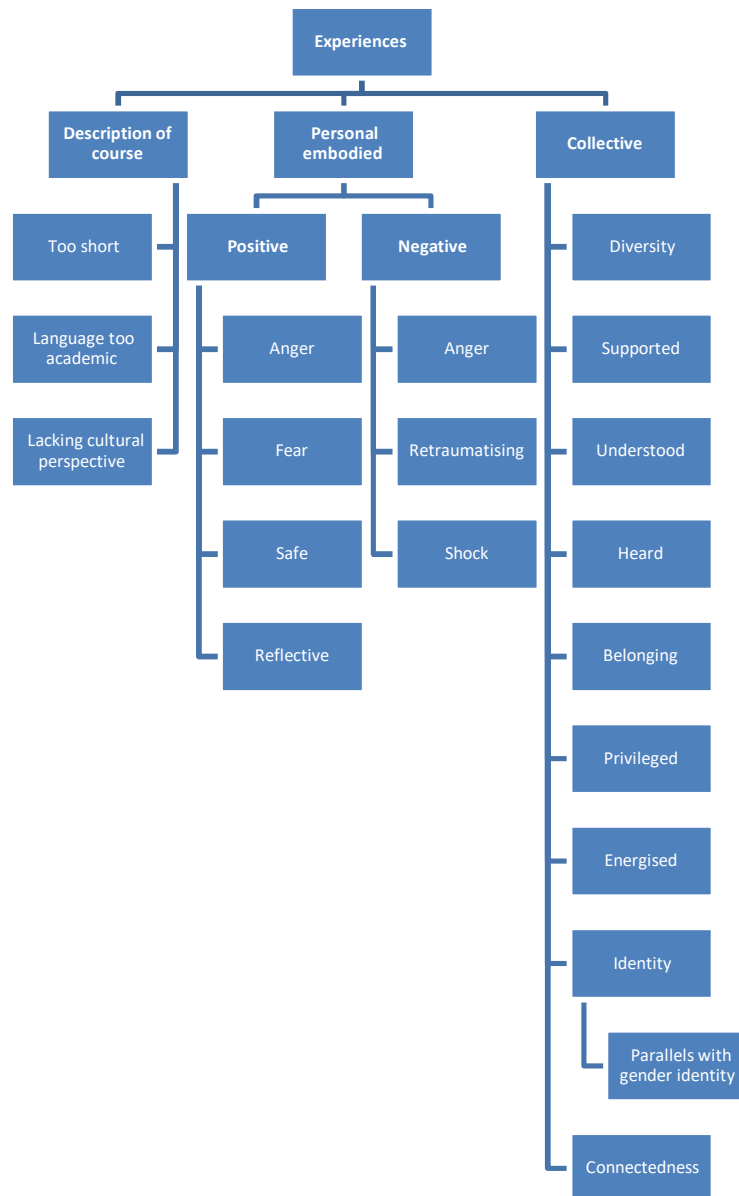


Themed map two: reclaiming Mad

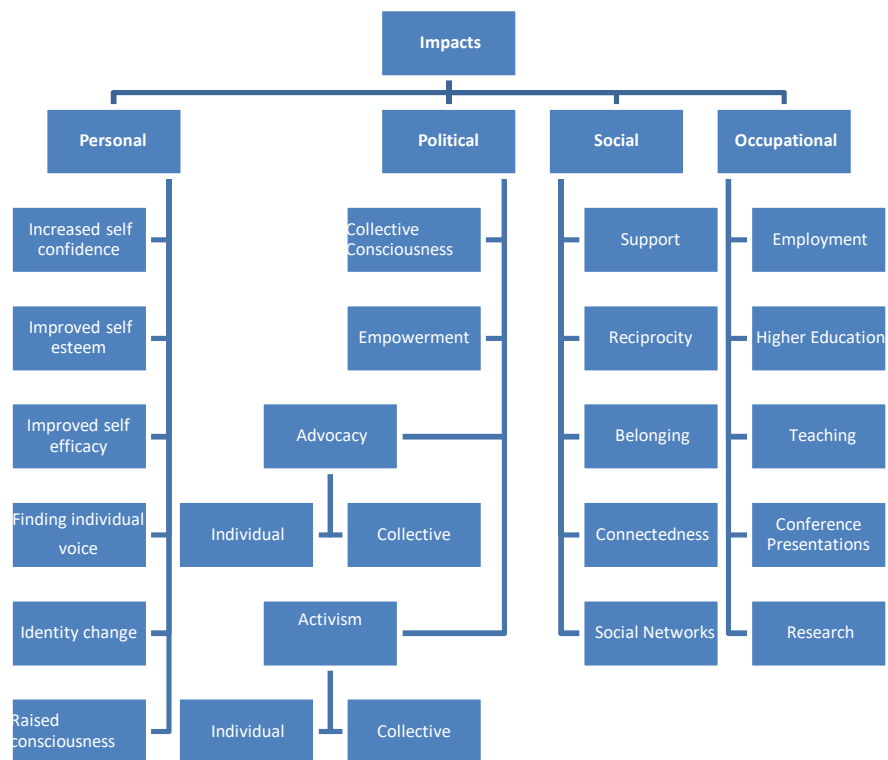




Themed map three: Mad History Photovoice



Themed map four: Experience of the course



Themed map five: Impacts of the course


## Appendix Eleven: Generative analysis images







## Appendix Twelve: Ethical approval

 <b>Queen Margaret University</b> EDINBURGH		
	Ref. Number	
	Assigned Reviewers	
	Outcome	<input type="checkbox"/> Granted <input type="checkbox"/> Amendments <input type="checkbox"/> Rejected
<b><u>APPLICATION FOR ETHICAL APPROVAL</u></b>		
<b><u>FOR A RESEARCH PROJECT</u></b>		
<p>This is an application form for ethical approval to undertake a piece of research. Ethical approval <u>must be gained</u> for any piece of research to be undertaken by any student or member of staff of QMU. Approval <u>must also be gained</u> by any external researcher who wishes to use Queen Margaret students or staff as participants in their research.</p>		
<p>Please note, before any requests for volunteers can be distributed, through the moderator service, or externally, this form <b>MUST</b> be submitted (completed, with signatures) to the Secretary to the Research Ethics Panel (<a href="mailto:ResearchEthics@gmu.ac.uk">ResearchEthics@gmu.ac.uk</a>).</p>		
<p>You should read QMU's Chapter on "Research Ethics: Regulations, Procedures, and Guidelines" before completing the form. This is available at:</p>		
<a href="http://www.gmu.ac.uk/quality/rs/default.htm">http://www.gmu.ac.uk/quality/rs/default.htm</a>		
<p>The person who completes this form (the applicant) will normally be the Principal Investigator (in the case of staff research) or the student (in the case of student research). In other cases of collaborative research, e.g. an undergraduate group project, one member should be given</p>		

responsibility for applying for ethical approval. For class exercises involving research, the module coordinator should complete the application and secure approval.

The completed form **should be typed** rather than handwritten. **Electronic signatures** should be used and the form should be **submitted electronically**.

**Checklist: Documents enclosed with application:**

*Please note that any application with missing relevant documentation will be returned to the applicant.*

Enclosed (please tick)	Not applicable (please tick)	Document name	
<input checked="" type="checkbox"/>	<input type="checkbox"/>	Research protocol or proposal	
<input checked="" type="checkbox"/>	<input type="checkbox"/>	Participant Information Sheet(s) (PIS)	
<input checked="" type="checkbox"/>	<input type="checkbox"/>	Participant consent form(s)	
<input type="checkbox"/>	<input checked="" type="checkbox"/>	Copies of recruitment advertisement material	
	<input checked="" type="checkbox"/>	Sample questionnaires (please detail below)	
<input checked="" type="checkbox"/>	<input type="checkbox"/>	Interview schedules or topic guides	
<input type="checkbox"/>	<input type="checkbox"/>	Letter(s) of support from any external organisations involved in the research	
<input type="checkbox"/>	<input type="checkbox"/>	If interacting with potentially vulnerable groups, please provide the following information for checks by authorised personnel:  PVG <sup>1</sup> Membership No: Disclosure Number (unique to each certificate): Date of issue:	
<input checked="" type="checkbox"/>	<input type="checkbox"/>	Risk assessment documentation	
<input type="checkbox"/>	<input type="checkbox"/>	Any other documentation (please detail below)	

<sup>1</sup> Protecting Vulnerable Groups – This membership scheme was introduced by the Scottish Government to improve disclosure arrangements for people who work with vulnerable groups. When you provide us with the certificate identification number for your PVG status, only authorised countersignatories for this scheme within the university will have access to your PVG records. The Research Ethics Panel and assigned reviewers will not have access or knowledge of your PVG records. Please be aware that if you are barred from working with the research population in your research application, and the PVG countersignatories have been made aware of your application, processes for Fitness to Practice will be triggered within the university.

<b>Section A: Applicant details</b>				
<b>A1. Researcher's name:</b> Elaine Ballantyne a. Senior Lecturer in Occupational Therapy b. Qualifications: BSc, MSc c. Contact email: EBallantyne@qmu.ac.uk				
<b>A2. Category of researcher (please tick and enter title of programme of study as appropriate):</b>				
<input type="checkbox"/>	QMU undergraduate student Title of programme:			
<input type="checkbox"/>	QMU postgraduate student – taught degree Title of programme:			
<input type="checkbox"/>	QMU postgraduate student – research degree			
<input checked="" type="checkbox"/>	QMU staff member – research degree			
<input type="checkbox"/>	QMU staff member – other research			
<input type="checkbox"/>	Other (please specify) Details:			
<b>A3. School:</b> Health Sciences				
<b>A4. Division:</b> Occupational Therapy and Arts Therapies				
<b>A5. Subject area:</b> Occupational Therapy				
<b>A6. Name of Supervisor or Director of Studies (if applicable):</b> EurigScandrett				
<b>A7. Names and affiliations of all other researchers who will be working on the project:</b>				
<i>First name</i>	<i>Last name</i>	<i>Position</i>	<i>Affiliation</i>	<i>Role on project</i>
		CAPS Project Worker	Partner in MPHl course	PAR group member
		Student	Student MPHl on	PAR group member
		Student	Student MPHl on	PAR group member
		Student	Student MPHl on	PAR group member
		Student	Student MPHl on	PAR group member
		Student	Student MPHl on	PAR group member
		Student	Student MPHl course on	PAR group member
<b>Section B: Research details</b>				
<b>B1. Title of study:</b> Doing Mad Studies: A Participatory Action Research Project to explore				



the experiences and impacts of being part of a Mad People's History and Identity course and to explore the relationship between critical education, activism and emancipation
<b>B2.</b> Expected start date: 23/3/2017
<b>B3.</b> Expected end date: April 2018
<b>B4.</b> Protocol or proposal version: (please follow naming format – ( <i>Mad Studies 20170215_version_number01</i> ))
<b>B5.</b> Protocol date: 15/2/2017
<b>B6.</b> Details of any grants/funding/financial support for the project from within/outside QMU: NA
<b>B7.</b> Do you plan at any stage of the project to undertake research involving adults lacking capacity to consent for themselves? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
<i>Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. If you answered yes, please refer to the online training module by University of Leicester and University of Bristol on 'Adults lacking capacity to consent for research' for further information: <a href="https://connect.le.ac.uk/alctoolkit/">https://connect.le.ac.uk/alctoolkit/</a></i>
<i>Your research may require approval by an authorised Research Ethics Committee (e.g. NHS Research Ethics Committee). If in doubt, please contact QMU Research Ethics Panel for further advice (<a href="mailto:ResearchEthics@gmu.ac.uk">ResearchEthics@gmu.ac.uk</a>).</i>
<b>B8.</b> Do you plan to include any participants who are children? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
<i>Answer Yes if you plan to recruit participants aged under 16. Please also ensure that question F6 is answered.</i>
<b>B9.</b> Do you plan at any stage of the project to work with human tissue samples (or other human biological samples) and data? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
<i>If you answered Yes to question B9, please also ensure that Section G is completed. To obtain a copy of Section G, please email <a href="mailto:ResearchEthics@gmu.ac.uk">ResearchEthics@gmu.ac.uk</a>.</i>

<b>Section C: Overview of the research</b>
<b>C1. Summary of the study.</b>
<i>Please provide a brief summary of the research (maximum 300 words) <b>using language easily understood by lay reviewers and members of the public.</b> Please note that this summary may be published in the public domain.</i>
<i>Mad Studies is a new area of study that promotes the knowledge, experiences and actions of people with lived experience of mental health issues referred to as Mad identified in this research.</i>
<i>This study proposes to explore the experiences and the impacts on students who attended a Mad Studies course here at QueenMargaretUniversity (QMU) titled “Mad People’s History and Identity” (MPHI). Congruent with the philosophy of the course the research is committed to privileging the experiences, knowledges and histories of the Mad identified students.</i>
<i>Participatory Action Research and Dialogical Research were chosen as methodologies due to their congruence with the MPHl course philosophy of critical pedagogy, co-production, inclusion, dialogue, collaboration and participation. Data collection will use qualitative and visual methods using interviews and Photovoice. Photovoice involves the students taking photographs of themselves or objects that represent their experiences. Students who have completed the course will be recruited to explore their experiences of the MPHl course. The research is in itself a Mad Studies project. The research therefore will have a focus on understanding the relationship between engagement in Mad Studies projects and the generation of knowledge. It aims to explore the relationship between engagement in the MPHl course, activism and emancipation from the student perspectives.</i>

Summary of main issues: *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them. Not all studies will raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by other review bodies (as appropriate to the issue). Studies that present a minimal*

<i>Autonomy will be a consideration. The students will be at all times voluntary participants in this process and will be informed that they can withdraw at any time from the interviews or exhibition:</i>
<i>1. Participation in the research is voluntary and requires prior informed consent (Appendix 2)</i>

<p>2. <i>Participation in the Photovoice exhibition is voluntary and requires additional prior informed consent (Appendix 4).</i></p>
<p><i>The students will be given information sheets about all of the data generation that they may be involved in see (Appendices 1, 3). They will also be asked to sign consent forms to participate in this research. Within the consent form it is important to clearly articulate the aims of the research, what the activity will involve, who the data will be disseminated to (Appendices 2, 4).</i></p>
<p><i>Anonymity will be addressed. Names will be changed on any reproduction of the written data. The Photovoice images and narratives in the exhibition will be anonymised. For photographs which identify individuals, these individuals will have the options of:</i></p>
<p><i>a) Including it in the exhibition</i></p>
<p><i>b) Including the image but manipulating it to anonymise it by shading of their face.</i></p>
<p><i>c) Removing the image from the exhibition.</i></p>
<p><i>Confidentiality will be addressed. The information gathered will be securely stored and the researcher will be the only person that has access to it. Files will be encrypted. Information will be destroyed after the research.</i></p>
<p><i>In visual methods participants are frequently not informed where their images will be disseminated. Consent will include information about the possible dissemination of their narratives and images. The images will not be used in additional exhibitions without providing information about the exhibition and seeking consent from the students. The images will be co-owned by the University, partners and participants. All parties must approve the reuse of the images in an exhibition. If any images are under copyright, permission will be sought from the artist prior to exhibiting outwith the University. It is not envisaged that engagement in research about their experiences of MPHl is invasive. The students who will volunteer to take part in this research have longstanding relationships with the researcher and CAPS advocacy. There will be pre-briefing and debriefing sessions incorporated in all data generation activities.</i></p>
<p><i>Durham University's (2012) ethical guide for Participatory research asserts that participatory research creates additional ethical challenges as the boundaries between researchers and participants become blurred. They advocate that Participatory Research needs to address additional ethical principles of: mutual respect, equality and inclusion, democratic participation, active learning, making a</i></p>

<i>difference collective action and personal integrity.</i>	
<i>This research has developed out of a four year relationship with activist's partners and students who created and participated in the MPHl course. Upholding these fundamental principles will be reviewed throughout this process using critical reflexivity and dialogue.</i>	
	<b>C2.C1.</b> <i>management issues arising from your study and say how you have addressed them. Not all studies will raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by other review bodies (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. should???</i>
	<b>C3.C2.</b> What is the principal research
	<i>Please put this in language comprehensible to a lay person.</i>
1.	<i>To understand the motivations, experiences and impacts of being involved in a Mad People's History course on Mad identified students.</i>
	<i>2. To develop a deeper understanding of Mad Studies as a critical pedagogy and its contribution to the generation of mad knowledge and the facilitation of activism from Mad People's History student perspectives.</i>
	<i>3. To ascertain the contribution of PAR to understanding the relationship between engaging in Mad People's History, activism and emancipation.is text box will expand as required.</i>
	<b>C4.C3.</b> What are the secondary research questions/objectives/aims if
	<i>Please put this in language comprehensible to a lay person.</i>
	<i>1. What motivated the students to be part of a Mad People's History course?</i>
	<i>2. What narratives do the students construct around their own mad history and mad identities?</i>
	<i>3. What are the experiences and impacts on the students of being part of a Mad People's History course?</i>
	<i>4. What can Participatory Action Research contribute to understanding the relationship between the engagement in a Mad Studies project, activism and emancipation?</i>
	<i>5. How can Participatory Action Research contribute to the advancement of mad peoples knowledges and the promotion of mad activism and Mad Studies?</i>

<b>C5.C4.</b> What is the academic/scientific justification for the research?	
<i>Please put this in language comprehensible to a lay person.</i>	
<p>This Mad Studies research aims to harness the expert and experiential knowledge of Mad identified students in designing and participating in research that generates survivor knowledge promotes survivor voices and creates both a visual and written history of the experiences and impacts of being involved in Mad Studies. There is currently a dearth of research on the experience of being part of this activist Scholarship. There is currently no Occupational Therapy literature on this emerging discourse.</p>	
<b><u>Section D: Design and Methodology</u></b>	
<b>D1.</b> Research procedures to be used: <i>please tick all that apply.</i>	
<b>Tick if applicable</b>	
<input type="checkbox"/>	Questionnaires ( <i>please attach copies of all questionnaires to be used</i> )
x	Interviews ( <i>please attach summary of topics or interview schedule to be explored</i> )
<input type="checkbox"/>	Focus groups ( <i>please attach summary of topics or interview schedule to be explored / copies of materials to be used</i> )
<input type="checkbox"/>	Experimental / Laboratory techniques ( <i>please include full details under question D2</i> )
<input type="checkbox"/>	Use of email / internet as a means of data collection ( <i>please include full details under question D2</i> )
<input type="checkbox"/>	Use of materials that are subject to copyright ( <i>please include full details under question D2 and confirm that the materials have been / will be purchased for your use</i> )
<input type="checkbox"/>	Use of biomedical procedures to obtain human tissues (or other biological materials) ( <i>please include full details under question D2 and Section G. Also include subject area risk assessment forms, where appropriate</i> )
x	Other technique / procedure ( <i>please include full details under question D2</i> )
<b>D2.</b> Please summarise your design and methodology.	
<i>It should be clear exactly what will happen to the research participant for research involving human participants. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol.</i>	

*The research will involve interviewing students who have completed the MPHl course. The four students who are part of the PAR group will be individually interviewed using a semi-structured interview schedule to generate themes about the experience of being on the MPHl course. Six to eight students who have completed the MPHl course will subsequently be invited to be interviewed individually by one member of the PAR group. Photovoice images chosen by the students as part of the assignment will be used to explore a deeper understanding of the experiences and histories of the students during the interviews. The interviews will be filmed and analysed by the student and the interviewer. The PAR group will carry out an additional analysis of the filmed interviews as a group. The research is underpinned by participation and action. There will also be an exhibition of the Photovoice images to promote the student voices.*

**D3.** Does your research include the use of people as participants?

☒ Yes

☐ No

**Answer No** if your project involves secondary analysis of collected data.

**If you answered Yes to question D3**, please ensure that Section F is completed.

**D4.** Does your research include the experimental use of live animals?

☐ Yes

☒ No

**If you answered Yes to question D4**, please note that the University is not insured to experiment on live animals. Please attach the insurance coverage certificate to this application for review. Please check and ensure that appropriate University insurance is in place to cover the work. If in doubt, please contact Karen Sinclair (Head of Finance, [ksinclair@qmu.ac.uk](mailto:ksinclair@qmu.ac.uk)) on insurance coverage.

**D5.** Does your research involve experimenting on plant or animal matter, or inorganic matter?

☐ Yes

☒ No

**If you answered Yes to question D5**, please check and ensure that appropriate University insurance is in place to cover the work. If in doubt, please contact Karen Sinclair (Head of Finance, [ksinclair@qmu.ac.uk](mailto:ksinclair@qmu.ac.uk)) on insurance coverage. Please attach the insurance coverage certificate to this application for review.

<b>D6.</b> Does your research include the analysis of documents, or of material in non-print media, other than those which are freely available for public access?	
<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
<p><b>If you answered 'Yes' to Question D6,</b> give a description of the material you intend to use. <i>Describe its ownership, your rights of access to it, the permissions required to access it and any ways in which personal identities might be revealed or personal information might be disclosed. Describe any measures you will take to safeguard the anonymity of sources, where this is relevant:</i></p>	
<b>D7.</b> Will any restriction be placed on the publication of results?	
<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
<p><b>If you answered 'Yes' to question D7,</b> give details and provide a reasoned justification for the restrictions. (See Research Ethics Guidelines Section 2, paragraph 7)</p>	
<b>D8.</b> Who will have access to participants' personal data during the study?	
<i>Where access is by individuals outside the research team or direct care team (health research), please justify and say whether consent will be sought.</i>	
NA	
<b>D9.</b> How long will personal or personally identifiable data be stored or accessed after the study has ended?	
<i>Please note this question only relates to retention of personal or personally identifiable data.</i>	
<input type="checkbox"/> Less than 3 months	
<input type="checkbox"/> 3 – 6 months	
<input checked="" type="checkbox"/> 6 - 12 months	
<input type="checkbox"/> 12 months – 3 years	

<input type="checkbox"/>	Over 3 years			
<p><i>It is recommended that data containing personal details that would lead to the identification of participants should be destroyed <b>as soon as possible</b>. Examples of personally identifiable data include participants' email addresses, NHS/CHI numbers, expressions of interest etc., BUT NOT consent forms. Personally identifiable data should be stored separate from the anonymised data to prevent linkage. If potential participants have provided you with their contact details, this information should only be retained until they have consented or refused to participate in the research. However, if a participant noted that they would like to receive a summary of the research, it would be appropriate to retain their contact details until this summary has been sent out.</i></p>				
See the following for advice on data handling: <a href="http://www.lancaster.ac.uk/shm/study/doctoral_study/dclinpsy/onlinehandbook/ethics_and_data_storage_advice/">http://www.lancaster.ac.uk/shm/study/doctoral_study/dclinpsy/onlinehandbook/ethics_and_data_storage_advice/</a>				
<p><b>D10.</b> For how long will you store research data generated by the study?          State if the data will be stored for an infinite time period.</p>				
<table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="padding: 5px;">Years: 5</td></tr> <tr><td style="padding: 5px;">Months:</td></tr> <tr><td style="padding: 5px;">More information:</td></tr> </table>	Years: 5	Months:	More information:	
Years: 5				
Months:				
More information:				
<p><b>D11.</b> Please give details of the <i>short term (duration of project)</i> and <i>long term (after project completion)</i> arrangements for storage of research data after the study has ended. (See Research Ethics Guidelines has Section 1, paragraph 2.4.1)</p>				
Short term storage of research data on any of the following:				
<input checked="" type="checkbox"/> Manual files (includes paper or film)				
<input type="checkbox"/> Home or other personal computers				
<input type="checkbox"/> University computers/server				
<input type="checkbox"/> Laptop computers				
<input type="checkbox"/> Hard drive storage				
<input type="checkbox"/> USB storage devices				



<input checked="" type="checkbox"/> Other portable storage (e.g. CDs, DVDs etc.)								
<input type="checkbox"/> Cloud/online storage (please provide name and server location of cloud storage below)								
<input type="checkbox"/> Others (please state):								
<table border="1"> <tr> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </table>								
Say where data will be stored	who will have access and the arrangements to ensure security (for example	encryption used). Explain how and when data will be destroyed (if applicable).						
Long term storage of research data on any of the following:								
<input checked="" type="checkbox"/> Manual files (includes paper or film)								
<input type="checkbox"/> Home or other personal computers								
<input checked="" type="checkbox"/> University computers/server								
<input type="checkbox"/> Laptop computers								
<input type="checkbox"/> Hard drive storage								
<input type="checkbox"/> USB storage devices								
<input checked="" type="checkbox"/> Other portable storage (e.g. CDs, DVDs etc.)								
<input type="checkbox"/> Cloud/online storage (please provide name and server location of cloud storage below)								
<input type="checkbox"/> eData – QMU open access data repository								
<input type="checkbox"/> Others (please state):								
Say where data will be stored, who will have access and the arrangements to ensure security (for example, encryption used). Explain how and when data will be destroyed (if applicable).								
<b>D12.</b> Will the data be stored:								
In fully anonymised form? (link to participant broken)								
<input type="checkbox"/> In linked anonymised form? (linked to data but participant not identifiable to researchers)								



of conducting the research.	
<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
If Yes, please give details.	
This text box will expand as required.	

<b>Section E: Risks and benefits</b>			
<b>E1.</b> Give details of all procedure(s) or intervention(s) that will be received by participants as part of the research protocol? <i>These include seeking consent, interviews, observations and use of questionnaires.</i>			
Please complete the columns for each procedure/intervention as follows:			
1. Total number of procedures/interventions to be received by each participant as part of protocol.			
2. Average time taken per procedure/intervention (minutes, hours or days)			
3. Details of who will conduct the procedure/intervention, and where will it take place.			
<i>Procedure or intervention</i>	<i>1</i>	<i>2</i>	<i>3</i>
Consent forms	2	20mins	Researcher in the University
Interviews	2	60 mins x2	Researcher in the University
<b>E2.</b> How long do you expect each participant to be in the study in total? <i>Duration of participation should be calculated from when participants give</i>			

Two hours
-----------

<i>informed consent until their last contact with the research team.</i>	
<b>E3.</b> What are the potential risks and burdens for research participants and how will you minimise them?	
<i>For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.</i>	
<i>Where the research only involves the use of data, consideration should still be given to the risks for participants associated with any breach of confidence or failure to maintain data security.</i>	
<b>E4.</b> Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?	
<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Not applicable	
If Yes, please give details of procedures in place to deal with these issues:	
<i>Distress is not anticipated due to the topic but participants can stop and withdraw at anytime. There will be briefing and debriefing sessions. Support from the researcher and partner at CAPS will be available box will expand as required.</i>	
<b>E5.</b> What is the potential for benefit to research participants?	
<i>You should state here any potential benefits to be gained by the research participant through taking part in the research either now or in future. However, do not over-emphasise the benefits. In some cases there may be no apparent benefit.</i>	
<b>E6.</b> Will the researcher be at risk of sustaining either physical or psychological harm as a result of the research? <i>Please delete as appropriate.</i>	
<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
If you answered 'Yes' to the question E6, please give details of potential risks and the precautions which will be taken to protect the researcher.	

*This text box will expand as required.*

### **Section F: Research Involving Human Participants**

***You should only complete this section if you have indicated above that your research will involve human participants.***

**F1.** Please indicate the total number of participants you intend to recruit for this study from each participant group:

<b>Participant Group</b>	<b>Please state total number</b>
QMU students	10- 12
QMU staff	
Members of the public from outside QMU	
NHS patients	
NHS employees	
Children (under 16 years of age)	
People in custody	
People with communication or learning difficulties	
People with mental health issues	
People engaged in illegal activities (eg. illegal drug use)	
Other (please specify):	

*\* Please declare in Question F8 where the participant group may necessitate the need for standard or enhanced disclosure check*

**F2.** How was this participant number decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation. If another method of determining participant numbers was used, please provide sufficient details for the method and justify the decision.*

**F3.** Please state the inclusion and exclusion criteria to be used. (See Research Ethics Guidelines Section 1, paragraph 2.4)

*Students who have completed the Photovoice assignment will be included.*

*Students who attended the course but did not complete the Photovoice assignment will be excluded.*


<b>F4. Will you obtain informed consent from or on behalf of research participants?</b>	
<input type="checkbox"/> Yes	XNo
<b>F5. Please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). <i>If you plan to include any participants who are children, please describe the arrangements for seeking informed consent from a person with responsibility and/or from children able to give consent for themselves.</i></b>	
If you are not obtaining consent, please explain why not.	
This text box will expand as required.	
<b>F6. Children)</b> If you intend to provide children under 16 with information about the research and seek their consent or agreement/assent, please outline how this process will vary according to their age and level of understanding. <i>Copies of written information sheet(s) for parents and children, consent/assent form(s) and any other explanatory material should be enclosed with the application.</i>	
For further information on providing information and obtaining consent/assent from children, please refer to this online information for best practice:	
<a href="http://www.hra-decisiontools.org.uk/consent/principles-children.html">http://www.hra-decisiontools.org.uk/consent/principles-children.html</a>	
This text box will expand as required.	
<b>F7. Will the research involve participant deception?</b>	
<input type="checkbox"/> Yes	XNo
<b>If you answered Yes to Question F7, please justify the use of deception. Also describe what procedures will be implemented to</b>	
This text box will expand as required.	
safeguard the dignity, safety and welfare of the participants during the research and after it has ended.	
<b>F8. Ethical principles incorporated into the study (please tick as applicable):</b>	


<b>Ethical principles</b>		
Will participants be offered a written explanation of the research? X Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable		
Will participants be offered an oral explanation of the research? X Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable		
Will participants sign a consent form? X Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable		
Will oral consent be obtained from participants? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable		
Will participants be offered the opportunity to decline to take part? X Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable		
Will participants be informed that participation is voluntary? X Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable		
Will participants be offered the opportunity to withdraw at any stage without giving X Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable		
Will independent expert advice be available if required? X Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable		
Will participants be informed that there may be no benefit to them in taking part? X Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable		
Will participants be guaranteed confidentiality? X Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable		
Will participants be guaranteed anonymity? X Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable		
Will the participant group necessitate a standard or enhanced disclosure of researcher? <input type="checkbox"/> Yes <input type="checkbox"/> No X Not applicable		
Will the provisions of the Data Protection Act be met? X Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable		
Has safe data storage been secured? X Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable		
Will the researcher(s) be free to publish the findings of the research? X Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable		
If the research involves deception, will procedures be in place during and after to safeguard the dignity, safety and welfare of the participants?		

<input type="checkbox"/> Yes	<input type="checkbox"/> No	X Not applicable
If the research involves questionnaires, will the participants be informed that they can skip any items they do not wish to answer?		
<input type="checkbox"/> Yes	<input type="checkbox"/> No	X Not applicable
If the research involves interviews, will the participants be informed that they do not have to answer questions, and do not have to give an explanation for this?		
X Yes	No	<input type="checkbox"/> Not applicable
Will participants be offered any payment or reward, beyond reimbursement of expenses?		
<input type="checkbox"/> Yes	X No	<input type="checkbox"/> Not applicable
<b><u>Section I: Declarations by applicant</u></b>		
<b>11.</b> Having completed all the relevant items of this form and, if appropriate, having attached the Information Sheet and Consent Form plus any other relevant documentation as indicated below, complete the statement below.		
<ul style="list-style-type: none"> <li>I have read QueenMargaretUniversity's document on "Research Ethics: Regulations, Procedures, and Guidelines".</li> </ul>		
<ul style="list-style-type: none"> <li>The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.</li> </ul>		
<ul style="list-style-type: none"> <li><u>In my view</u> this research is:</li> </ul>		
<i>Please tick</i>	<i>See Research Ethics Guidelines Section 6</i>	
x	Non-invasive	
<input type="checkbox"/>	Minor invasive using an established procedure at QMU	
<input type="checkbox"/>	Minor invasive using a NEW procedure at QMU	
<input type="checkbox"/>	Major invasive	
<ul style="list-style-type: none"> <li>I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.</li> </ul>		
<b>12.</b> Access to application for training purposes (please tick as appropriate):		



<input type="checkbox"/> I would be content for members of Research Ethics Committees to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.	
Name (if you have an electronic signature please include it here)	
E Ballantyne Date __15/2/2017____	
<b>13. If you are a student</b> , show the completed form to your supervisor/Director of Studies and ask them to sign the statement below. If you are a member of staff, sign the statement below yourself.	
<ul style="list-style-type: none"> <li>I am the supervisor/Director of Studies for this research.</li> </ul>	
<ul style="list-style-type: none"> <li><u>In my view</u> this research is:</li> </ul>	
Please tick	See Research Ethics Guidelines Section 6
<input checked="" type="checkbox"/>	Non-invasive
<input type="checkbox"/>	Minor invasive using an established procedure at QMU
<input type="checkbox"/>	Minor invasive using a NEW procedure at QMU
<input type="checkbox"/>	Major invasive
<ul style="list-style-type: none"> <li>I have read this application and I approve it.</li> </ul>	
Name (if you have an electronic signature please include it here)	

  
Date _____
<p><b>14. For all applicants,</b> send the completed form to your Head of Division or Head of Research Centre or, if you are an external researcher, submit the completed form to the Secretary to the QMU Research Ethics Panel (<a href="mailto:ResearchEthics@qmu.ac.uk">ResearchEthics@qmu.ac.uk</a>). <b>You should not proceed with any aspect of your research which involves the use of participants, or the use of data which is not in the public domain, until you have been granted Ethical Approval.</b></p>
<b>For completion by</b>
<b>The Head of Division/Subject Area/Group, OR</b>
<b>Division/Subject Area/Group Research Ethics Committee:</b>
<i>Either</i>
<input type="checkbox"/> I refer this application back to the applicant for the following reason(s):
Name <i>(if you have an electronic signature please include it here)</i>
_____ (Head of Division/ Subject Area/ Group)
Date _____

Please return the form to the applicant.
Or
Please tick <b>one</b> of the alternatives below:
<input type="checkbox"/> I refer this application to the QMU Research Ethics Panel.
<input type="checkbox"/> I find this application acceptable and an application for Ethical Approval should now be
submitted to a relevant external committee.
<input checked="" type="checkbox"/> I grant Ethical Approval for this research.
Name (if you have an electronic signature please include it here)

_____ (Head of Division/ Subject Area/ Group)
Date ____ 02/03/2017 ____
Please email one copy of this form to the applicant and one copy to the Secretary to the Research Ethics Panel ( <a href="mailto:ResearchEthics@qmu.ac.uk">ResearchEthics@qmu.ac.uk</a> ).
Date application returned: _____

## Appendix Thirteen: Interview information sheet and consent form

### Doing Mad Studies



Queen Margaret University  
EDINBURGH

#### A Participatory Action Research Project

My name is Elaine Ballantyne. You will know me as the course leader of the Mad People's History and Identity (MPHI) course you attended here at Queen Margaret University. I am also a Professional Doctorate research student from the School of Health Sciences at Queen Margaret University in Edinburgh. As part of my Doctorate I am undertaking a research project. The title of my project is:

Doing Mad Studies: A Participatory Action Research Project to explore the experiences and impacts of being part of a Mad People's History and Identity course and to explore the relationship between critical education, activism and emancipation.

The study is a Participatory Action Research Project that has involved partners from CAPS and students from MPHI working with me in partnership to design research that will explore the experiences of students who attended the course and the impacts of participating in the course.

We are particularly interested in:

- What motivated you to be part of the course?
- What were your experiences on the course?
- Were there any impacts for you as a result of participating in the course?
- Why did you select the Photovoice image for your assignment and how does this relate to your own experiences and history?

It is anticipated that the findings will be valuable as research has not explored the views of students engaging in this new area of study. The use of your images will generate new knowledge about this course and how it relates to your own experiences and history. We anticipate that this research will promote the voices, issues and histories of Mad People's History students and provide information on the impacts of participating in a Mad People's History course.

If you take part in this study, you will be asked to explore your experiences by taking part in an individual interview. You will also be asked to discuss your Photovoice image and how this relates to your own experiences and history. The interview will be filmed (with your permission). With the interviewer you will both watch the film. We think it is important that you identify the messages that are important to you from the interview. The overall process will take place over two sessions no longer than 1 hour each.

You will be interviewed by one member of the team. The team consists of:

Eleanor

Shona

Patricia

Niamh

Lorraine

The researcher is not aware of any risks associated with this study. You will be free to withdraw from the study at any stage and will not have to give a reason. You will also have choice in who interviews you without giving a for your selection.

All data from the interviews will be anonymised as much as possible. Your name will be replaced with a pseudonym and it will not be possible for you to be identified in any reporting of the data gathered. If your image is a photograph of you additional consent will be sought before it is used and you will have the option to shade your face in the image.

The results of the research, including your anonymised images and interview information may be published in a journal or presented at a conference. Additionally they may be used to educate students about Mad People's History and to promote the course.

The film of your interview will not be used in any activities.

If you have read and understood this information sheet, any questions you had have been answered, and you would like to be a participant in the study, please now see the consent form.

For support with any issues arising from this research you can contact the researcher or Kirsten McLean at CAPS Independent advocacy service for support

[Kirsten Maclean](#)

[Community History Worker](#)

[Oor Mad History, CAPS Independent Advocacy.](#)

#### **Contact details of the researcher**

Name of researcher: Elaine Ballantyne

Address: School of Health Sciences  
Queen Margaret University, Edinburgh  
Margaret University Drive  
Musselburgh  
East Lothian EH21 6UU

Email / Telephone: [Eballantyne@qmu.ac.uk](mailto:Eballantyne@qmu.ac.uk). Tel 0131 474 0000

Many Thanks  
Elaine Ballantyne

## **Interview consent form**

### Doing Mad Studies



Queen Margaret University  
EDINBURGH

A Participatory Action Research Project

I have read and understood the information sheet and this consent form. I have had an opportunity to ask questions about my participation.

I understand that I am under no obligation to take part in this study.

I understand that I have the right to withdraw from this study at any stage without giving any reason.

I agree that the information from my interviews and images can be used in publications, presentations and educational activities related to this project.

I agree for my photograph to be used in publications, presentations and educational activities related to this project.

I agree to participate in this study.

Name of participant:

---

Signature of participant:

---

Signature of researcher:

---

Date:

---

Contact details of the researcher



Name of researcher: Elaine Ballantyne

Address: Division of Occupational Therapy and Arts Therapies

Queen Margaret University, Edinburgh

Queen Margaret University Drive

Musselburgh

East Lothian EH21 6UU

Email / Telephone: [Eballantyne@gmu.ac.uk](mailto:Eballantyne@gmu.ac.uk) . Tel: 0131 474 0000

## **Appendix Fourteen: Information sheet and consent form Photovoice Exhibition**



Queen Margaret University  
EDINBURGH

### **Mad People's History Photovoice Exhibition**

My name is Elaine Ballantyne. You will know me as the course leader of the Mad People's History and Identity (MPHI) course you attended here at Queen Margaret University. I am also a Professional Doctorate research student from the School of Health Sciences at Queen Margaret University in Edinburgh. As part of my Doctorate I am undertaking a research project. The title of my project is:

**Doing Mad Studies: A Participatory Action Research Project to explore the experiences and impacts of being part of a Mad People's History and Identity course and to explore the relationship between critical education, activism and emancipation.**

As part of the research we would like to organise an exhibition of your Photovoice images from the MPHI course.

We are particularly interested in:

- The Photovoice image for your assignment
- Your written account of how this image relates to your experiences and history?

It is anticipated that the exhibition will generate new visual and written knowledge that promotes the voices, issues and histories of Mad People's History students and promotes the course.

The exhibition will take place in the Piano Bar at Queen Margaret University on the 23<sup>rd</sup> March. MPHl students, partners, academics, policy makers and supporters of this work will be invited to attend.

The researcher is not aware of any risks associated with your image being part of this exhibition. You will be free to withdraw your work from the exhibition at any stage and will not have to give a reason.

You do not need to provide a written explanation of your image. All written information can be anonymised or be replaced with a pseudonym. If your image is a photograph of you additional consent will be sought before it is used and you will have the option to shade your face in the image.

The anonymised images and writing may be published in a journal or presented at a conference. Additionally they may be used to educate students about Mad People's History and to promote the course.

Your image will not be used at future exhibitions without you being provided with information and providing consent.

If you have read and understood this information sheet, any questions you had have been answered, and you would like your work to be part of the exhibition, please now see the consent form.

Many Thanks  
Elaine Ballantyne

Consent form Photovoice Exhibition



Queen Margaret University  
EDINBURGH

### **Mad People's History Photovoice Exhibition**

I have read and understood the information sheet and this consent form. I have had an opportunity to ask questions about my participation.

I understand that I am under no obligation to take part in this study.

I understand that I have the right to withdraw from this exhibition at any stage without giving any reason.

I agree that my image and written information about my image can be used in publications, presentations and educational activities related to this project.

I agree for my photograph to be used in publications, presentations and educational activities related to this project.

I agree to participate in this study.

Name of participant:

\_\_\_\_\_

Signature of participant:

\_\_\_\_\_

Signature of researcher:

\_\_\_\_\_

Date:

\_\_\_\_\_

Contact details of the researcher

Name of researcher: Elaine Ballantyne

Address: Division of Occupational Therapy and Arts Therapies

Queen Margaret University, Edinburgh

Queen Margaret University Drive

Musselburgh

East Lothian EH21 6UU

Email / Telephone: [Eballantyne@gmu.ac.uk](mailto:Eballantyne@gmu.ac.uk) Tel: 0131 474 0000

## Appendix Fifteen: Film consent



Queen Margaret University  
EDINBURGH

### Photography/ Filming Consent Form

I hereby agree to Queen Margaret University taking photograph(s)/ film footage of me/my child/family. I assign Queen Margaret University, the copyright of the video footage/images in which I feature.

Queen Margaret University may reproduce the photographs/video footage, and use in any way it decides, altered or otherwise, without claims, demands or proceedings by me. This includes sharing of the photograph with third party organisations (eg Universities Scotland, the body which represents the higher education sector).

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Please note that if you complete the approval form, and Queen Margaret University subsequently uses your image on online or in printed material, we are under no obligation to remove that image in the future.

#### 1: To be completed by model

Dated:

Name (please print)

.....

Course (If App)

.....

Email/ Contact Number:

.....

Signed

.....  
..

**2: To be completed by QMU (Photographer)**

Photographer/Videographer Name (printed)

Location of photography:

QMU Campus

Description of photography/film footage and model (including time stamp, if multiple models)

Image or Video File ID:

Time Stamp: .....

.....

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The image/ film will be held in our Marketing & Communications Office if you wish it removed  
please let us know by contacting: Marketing & Communications, Queen Margaret University, Queen Margaret  
University Drive,  
Musselburgh, EH21 6UU. Tel 0131 474 0000 Fax 0131 474 0001. [Emailmarketing@qmu.ac.uk](mailto:Emailmarketing@qmu.ac.uk)